



## **A Deaf Child in the Family**

A preliminary study of the social-emotional impact of deafness on parenting and family life in Cape Town

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## Abstract

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This study documents hearing parents' experiences of the impact of deafness on raising their deaf children during the preschool years. It focuses on their experience of health services for their child. The study population of 20 children was drawn from parents with children under 6 years of age diagnosed with moderate to profound loss of hearing at the Developmental Clinic, Red Cross Children's Hospital, Rondebosch, Cape Town.

Data was collected from 2 sources, namely a semi-structured interview, which was analysed for themes, and a questionnaire, which measures parental stress, communication difficulties, and experience of professional support.

Chapter four summarises demographic characteristics of the parents and children.

Chapters five to nine documents the results (key themes) which emerged from analysis of the data: Chapter five outlines enablers and barriers to early detection, help-seeking and diagnosis of deafness in the child. Chapter six discusses the impact of the quality of professional communication, and of parental readiness for this news, on parents' experience of receiving news about their child's deafness. Chapter seven outlines sources of stress for parents of a deaf child. Chapter eight focuses on parental difficulties in communicating with the child, and chapter nine identifies areas where communication difficulties may pose problems in parents' experience of child-rearing.

Chapter 10 discusses selected themes from the results section as they relate to the study objectives. Chapter eleven elaborates on the following key recommendations for improving services to deaf children and their parents:

- Development of a comprehensive service for deaf children,
- improving assessment, detection and diagnosis of deafness in young children,
- equipping health workers for effective communication with parents,
- developing cost effective options for providing emotional support,
- improving parents access to available financial and social support,
- development of locally informed guidelines for assisting parents and service providers in communication choices,
- preparing parents for educational choices,
- learning from the experience of adult Deaf,
- providing opportunities for improving parenting skills, and
- developing a local research agenda for improving services for the deaf child.

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## **A Deaf child in the Family**

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## **One**

### **Introduction**

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*"...reminding us that between every set of headphones lies more than a pair of ears, and that in the last analysis it is human beings dealing with other human beings that affects, for better or worse, the human condition."*

In: David Luterman, 1979, *Counselling Parents of Hearing-Impaired Children*, page xi.

#### **1.1 Deaf people in South Africa**

Reliable statistics on the prevalence, incidence and aetiology of deafness is difficult to obtain (World Health Organisation, 2002). The World Health Organisation's (WHO) report on Primary Ear and Hearing Care (48<sup>th</sup> World Health Assembly), estimates that approximately 120 million people worldwide have a hearing disability (WHO, 1998). The WHO internet site, updated April 2002, reports that approximately 250 million people worldwide have a disabling hearing impairment. Two thirds of these people live in developing countries. Specific prevalence rates aside, it can be seen that a significant number of people in the world are estimated to be hearing disabled.

In South Africa, disability issues were poorly addressed during the apartheid era, including the collection of information on the incidence and prevalence of disability in the country. Current post- apartheid initiatives at gathering prevalence rates on disability are in their infancy. They do not necessarily provide reliable indicators of the disabled sector of the population as a result of underreporting due to stigma, the lack of identification of disability, and lack of rigor in defining and identifying disabled people (Disabled People South Africa, 2000).



Census data provide some measure of disability in the country, although figures given may be underestimations. (DPSA, pg 43, 2000). The Census 1999 Household Survey data (Statistics South Africa, 2000) estimates a prevalence of 63/1000 people with some degree of deafness nationwide, with 56% of these people living in urban settings, and 44% living in non – urban settings<sup>1</sup>. Approximately 2% of this group was estimated to be under 5 years old, 8% between the ages of 5-9 years old, a total of 10% under the age of 10 years, and 19% between the ages of 10 –19 years. The report is not clear on the degree to which the steady increase in the rate of deafness in children as they grow older represents new cases of deafness due to untreated health conditions or environmental traumas, or <sup>2</sup> existing cases which were previously undetected. Approximately 14% of deaf people reported having access to medical aid for their health needs, while approximately 86% of urban and non-urban based deaf people would need to use public health services.

The Deaf Federation of South Africa (DEAFSA, 1995) estimates that approximately 70% of the total South African deaf and hard of hearing population is unemployed. 68% of deaf and hard of hearing people live in informal housing, with income and subsistence levels 40% lower than the hearing people in their communities.

Potgieter (1998) estimates that countywide, approximately 4 million people, or 10% of the South African population, are deaf or hard of hearing, an estimate endorsed by DEAFSA.

Census 2001 figures estimates that the total population with a severe disability as a result of hearing loss is 0,7% of the population. This is 5%<sup>3</sup> of the national total for all disabilities.

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<sup>1</sup> Deaf Blind South Africa estimates that approximately 4000 - 6000 South Africans are deafblind, of whom approximately 10% are children. (Deaf Blind SA, Website, January 2004), but this group is not the focus of this study, which looks at children who are deaf only.

<sup>2</sup> WHO estimates that 50% of the deafness in 120 million deaf persons worldwide could have been prevented with adequate primary hearing care, supported by health education and promotion programmes. Chronic ear disease, infectious diseases of childhood, noise, ototoxicity and consanguinity are listed as the most common causes of hearing loss or deafness (WHO, 1998).

<sup>3</sup> Census 2001 data defines disability very specifically, as a "physical or mental handicap lasting for 6 months or more, and expected to last at least 6 months, which prevents the person from carrying out daily activities independently or from participating fully in educational, economic or social activities. The definition differs from the definition used in the 1996 Census, so that figures are not directly comparable.

The importance of good public health services for people with hearing difficulties cannot be overemphasised, given that the majority of deaf people are uninsured people who will need to access health services at public health institutions.

### **1.1.1 Deaf people in the Western Cape Province (WCP)**

The Western Cape has a population of approximately 4, 524 million people or 10,1% of the population of the country (Census 2001, 2003), up from the Census 1996 data of 3,956 million people.

The Census 2001 data (2003) estimates that of a total of 186 850 persons with a physical or mental impairment in the province, approximately 26 492 (14%) people have a hearing impairment.

### **1.2 Hearing parents and deaf children**

Most parents want nothing more than for their child to make steady progress through childhood, toward a happy, secure and independent life as adults. The well-being of children are centrally influenced by the nature of the parent - child relationship<sup>4</sup>, (Ainsworth, 1978, Luterman, 1979, Bowlby, 1988, Richter 2001), and the quality and orientation of psychosocial, economic and environmental supports available to parents (Beazley & Moore, 1995).

The emotional experience of the parent-child relationship is mediated by factors *within the child and parent*. Factors in the child may include, for example, the child's physical, intellectual and emotional make up, resilience, temperament and relational style. Within the parents, these factors may include, for example, values, beliefs, attitudes, life experiences, parenting styles and skills.

Psychosocial, economic and environmental supports *within the social milieu* in which children and parents live also impact on the emotional experience of parent-child interaction. These factors are elaborated in chapter 2.

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<sup>4</sup> The term parent will be used to denote the person(s) which have primary responsibility for the care and well being of the children in their homes, in this study, mothers, fathers and, sometimes, grandmothers.

In the context of this study, these personal, interpersonal, familial and broader social constructs constitute the *social environment* within which children and parents' experience themselves, their roles and their relationships in the world. Parents' understanding and emotional processing of these experiences constitute the *emotional environment* which influences parents' response to this social environment. These social and emotional environments interact to co-construct a *social-emotional* context which impacts on the experience of parenting.

The discovery that their child is deaf, for example, may present a significant social-emotional challenge to hearing<sup>5</sup> parents as they raise their child. Hearing parents may initially process the news that their child is deaf from a deficit-based perspective on what this may mean for them and their child. The children's parents', service providers' and the community's view of deafness and Deaf issues can influence the ease with which parents approach the challenges which lay ahead. (National Information Centre on Deafness, 1991).

### 1.3. Objectives of the study

Parental views on their experiences of raising a deaf child can provide support to other parents with deaf children (Gregory, 1995, The National Deaf Children's Society, 2003). Beazley and Moore (1995) view parents' perspectives as central to the development of policies and strategies to address child, parent and family needs. This study examines the difficulties and lessons learnt by local hearing<sup>6</sup> parents of deaf children, their experiences of services provided, and their service needs. Specifically, it provides comment on:

- parental **attitudes toward deafness** in general, their child's deafness in particular, and the impact of these attitudes on parental coping with the child's deafness,

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<sup>5</sup> A distinction is often made between audiological deafness (deaf), and cultural Deafness (capitalized Deaf), as detailed in Chapter 2. Different meanings are assigned to the use of these terms by different people. In this study, non-capitalisation will be used to refer to deafness and hearing as measured audiometrically, and Deaf as a signifier for a cultural identity shared by some Deaf and hearing people.

<sup>6</sup> Issues pertinent to the Deaf parent raising a deaf or hearing child is not addressed in this study.

- parents' perceptions of the impact of deafness on **marital and family functioning**, if any,
- **psychosocial issues** hearing parents may experience in raising their deaf child,
- **child-rearing issues** experienced by parents as a consequence of the child's deafness,
- parental **exposure to and experience of services** available to them and their child and perceived usefulness of these services for their needs, and
- **preliminary recommendations for improving services** for parents, with a specific focus on the health sector.

### 1.3.1 Study design

An *advocacy/participatory perspective* influenced the conceptualisation and design of the study. This perspective advocates the empowerment of people with disabilities by advancing change which will improve their quality of life and participation in society (Creswell, 2003). A *phenomenological approach* guides the interpretation of parental experiences while a *pragmatic approach* guides the researchers interrogation of these experiences to derive practical recommendations to address the needs of parents and their children (Creswell, 2003). A mixed methods approach was used to generate the data for the study: Semi-structured interviews and a questionnaire were used to elicit parental experiences (Meadows-Orlan, 1990; Hudelson, 1996; Schurink, 1998; Creswell, 2003; Mayan, 2001). An adaptation of the "grounded theory" approach was used to analyse and interpret the textual data of the interviews (Glaser and Strauss, 1967; Poggenpoel, 1998; de Vos & van Zyl, 1998). Descriptive statistics were derived from the questionnaire results. The research design is expanded in Chapter Three.

### 1.3.2 Limits of the scope of the study

Parents, particularly those of children with special needs, most frequently engage with the health sector, social service sector and education sector for support in the early years of the child's development. Health is usually the sector with which new parents first engage for support and this is the sector on which this study focuses. The educational and social service sector will not be extensively addressed, although the essential, intersectoral roles of these sectors for child services is acknowledged.

The World Health Organisation and its member states suggests that the health sector pay more attention to the introduction of strategies for capacity development (knowledge and skills development, treatment protocols and guidelines) to address preventable causes of deafness. They emphasize the need for these developments at the Primary Health Care (PHC) level of service. A workshop in Cape Town, South Africa in 1998 focused on the need to develop a PHC Ear and Hearing Care programme in Sub-Saharan Africa to reduce the incidence of preventable deafness (WHO, 1998). The prevention of potentially disabling hearing loss is a central health care concern, but will not be addressed in this study, where the focus is on supporting parents of preschool children who are already deaf. The sample is drawn from uninsured, poor parents living in and around the Cape Town area who have deaf children under the age of 6 years. Recommendations for improvement to the services offered by the health sector will therefore focus on poorer, urban based families who use public health services in the Metropolitan Region of the province, and may not be generalisable to all parents and deaf children in the Western Cape.

#### **1.4. The national context for disability, deafness in children, and their access to health services.**

The Constitution of the Republic of South Africa, 1996, and the equality provisions of the Bill of Rights in particular, legislates for access and participation of disabled persons in all aspects of public life in South Africa. The White Paper on an Integrated National Disability Strategy (November 1997), and the Integrated Provincial Disability Strategy of the Western Cape (November 2002) makes reference to participation and access to services by the Deaf, in particular stressing the importance of communication enablement via Sign Language and/or the use of assistive devices. South Africa is also a signatory to the United Nations Convention on the Rights of the Child (June 1995). South Africa is also guided by the National Programme of Action for Children, 1996, which outlines the focus of South African action to actualise these rights. This plan includes the development of programmes to address the needs of children with disabilities.

The 2002 Hearing Screening Position Statement of the Professional Board for Speech, Language and Hearing Professions (Health Professions Council of South Africa, December 2002) outlines a comprehensive approach to targeted (risk based) newborn hearing screening (TNHS). It recommends that TNHS should be implemented within the district health service, to target 98% of babies under 6 weeks by 2010. It also spells out an Early Hearing Detection and Intervention Programme (EHDI) to reduce the age of identification, diagnosis and intervention for deaf children. Goals set for this programme include:

- Diagnosis of hearing loss by age 3 months.
- Parent education on options of communication by 3 months.
- Parent education and support available to enable parents to assume a central role in the habilitation process.
- Referral and intervention by 6 months.
- Access by infants at risk for hearing loss to regular audiological and medical monitoring for the first 3 years, and at intervals thereafter.
- Use of less reliable behavioural and paper and pen methods of detection only if augmented by electrical and electrophysiological tests, and replacement of noise-making methods (rattles, whistles) by these tests.
- Primary health care worker capacity (appropriate technology and training) for early detection and diagnosis to be improved.
- Secondary level audiological assessment services and intervention programmes to be available and accessible to children with hearing impairment.

#### **1.4.1 Public healthcare in South Africa**

Healthcare reform in South Africa enters its 10<sup>th</sup> year in April 2004. During that time changes have been effected in both the medical aid funded private sector and the public health sector. Private healthcare serves under 28% of the population and uses the bulk of available health care resources. The public sector serves approximately 72% of the population with a relatively small purse. The primary health care approach aims to transform public services from a fragmented, racially iniquitous, inaccessible and unaffordable system of mainly hospital based health care focused on curative services, to district based prevention, treatment and rehabilitation services. These district

services will be offered through a network of home based, community, clinic and hospital services throughout the country. (White paper on the Transformation of the Health System, April 1997). Health-related services for deaf persons should be integrated within this system, on par with services provided for other health needs.

#### **1.5. The Provincial context for health services for deaf children.**

1.6.

##### **1.5.1 *The socio-economic profile of the Western Cape Province***

The Western Cape Province (WCP) is one of 9 provinces in South Africa. Citizens live primarily in the smallest, urban metropolitan region (68%). The remaining 12% are fairly equally divided among the 3 larger, rural and peri-urban regions, the Boland Overberg region, the Southern Cape Karoo region and the West Coast Winelands region. In the Metropol, poverty, high unemployment and poor living and health conditions exist in sprawling informal settings within which mainly Black citizens (26,7% of the population of the WCP), and an emerging population of refugees live. Working class conditions prevail on the Cape Flats which sweep down from below Table Mountain, where predominantly "Coloured" (53,9%), Indian (1%) and some Black citizens live. More affluent suburbs which circle Table Mountain, beach-rich and wine-growing areas in the Metro are predominantly owned by White (18,4%) citizens. In rural regions, health workers have to cover wide geographical areas between towns and farming communities, with fairly racially divided poverty and affluence living side by side.

##### **1.5.2 *Public healthcare in the Western Cape Province***

The province's public health sector provides for health needs of the uninsured 72% of its 4,5 million citizens

###### **1.5.2.1 *Organisation of services***

The WCP currently has a provincial policy, planning and programme development office in Cape Town, and 4 regional offices, one per region, which manages the health budget and implementation of health services in each region.

The WCP currently provides mainly curative care in its provincial primary health care clinics, community health centres and hospitals. Mainly preventative care is offered at local authority clinics. The province is in the process of finalising its district and subdistrict structures. These are earmarked for phase-in during 2004, and which will also effect the amalgamation of these two services. Tertiary hospital services and expertise are located in the Metro only, with secondary and district hospital services available in each region. The province also has service level agreements with non-profit organizations (NPOs) to provide specific services to patients within community and homecare settings.

### **1.5.3 Services for deaf children in the Western Cape Province**

Local services for the deaf are few, and for children, are primarily concerned with early language development and schooling. Speech training (oral communication) or a combination of speech and signs (total communication) is most often used as the medium of instruction. There is a dearth of tertiary training facilities for deaf persons<sup>7</sup>, and with the exception of a few, most deaf school-leavers face unemployment or fill unskilled or semi-skilled jobs. Psychological support services for parents raising children in this inadequate environment are only available from the few assessment and early intervention clinics and schools.<sup>8</sup>

#### **1.5.3.1 Health services for the deaf child**

##### **Primary level care**

Standardised screening tools and implementation guidelines for developmental assessment of children at 6 weeks, 9 months and 18 months were developed and

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<sup>7</sup> The Deaf Institute in Worcester, WCP, launched Deaf College Africa in 2000 which, in partnership with Cape Technikon and the University of Stellenbosch, trains Deaf students to work in the tourism and hospitality trade to improve language accessibility for Deaf foreign and local tourists visiting South Africa (Deaf Institute, 2001). The University of the Witwatersrand provides support services for Deaf students studying at the university (DEAFSA, 1995). DPSA, DEAFSA (WCP) and Western Cape Education Department are planning to pilot a training programme for deaf pupils within the 3 campuses of the False Bay College for Further Education and Training in the Metropol Region of the WCP (Personal Communication, Meryl Glazer, 13/02/2004)



piloted by the Provincial Maternal, Child and Women's Health (MCWH) Subdirectorate in the Department of Health from 1996-1998 (Circular H.159/99, 23 December 1999, Department of Health, WCP). The tools have been implemented within the primary health sector in each of the 4 health regions in the province since December 1999, following training provided by the regional human resource development and training offices. Appendix One lists the questions asked for detection of deafness in the tools.

Paediatric case management guidelines, including a guideline for the management of upper respiratory tract infections (including ear infections) has also been developed by the MCWH Programme, in line with the WHO and UNICEF (United Nations Children's Fund) guidelines on Integrated Management of Childhood Illnesses (IMCI), for the management of priority childhood conditions in developing countries (Circular H93/2001, 26 September 2001, Department of Health, WC).

#### Evaluation of the screening tools

The Provincial Maternal, Child and Women's Health (MCWH) Subdirectorate commissioned an evaluation of the implementation of the developmental screening programme (DSP) in the WCP (Child Health Unit, November 2003). The key findings of the evaluation report are that:

- there is good overall awareness of the DSP in health facilities,
- the delivery of the DSP is occurring to a limited extent in the province,
- despite an intensive provincial training programme during the initial implementation of the DSP, there are significant gaps in the training and support of health workers in the use of the tools, as a result of limited human resource development capacity at regional level,
- assessments of children are not always done according to protocol (Problems of partial screening, screening of other age groups, use of old screening tools, etc),
- referral of children is also not always done according to protocol (Lack of disability services at secondary facilities, bypassing secondary facilities, and lack of adequate referral to rehabilitation services).

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<sup>8</sup> DEAFSA (1995) found that nationally 28 social workers, 3 psychologists, 3 audiologists and 3 community nurses in South Africa had adequate communication skills in Sign Language to provide services to the Deaf and hard of hearing person.

### Secondary level care

As a result of increased awareness through the developmental screening programme, the HARK project<sup>9</sup>, and the increased emphasis in the WCP of the need to strengthen district based services (Healthcare 2010, 2003), the health regions of the Western Cape have, or are in the process of appointing, speech therapists based at secondary hospitals. ENT sessional services are available at some secondary hospitals in the province, and outreach audiology support is offered to selected secondary hospitals from the tertiary hospitals. (Personal communication Ms Leana Olivier, 09/02/2004 provincial coordinator for MCWH, Department of Health, Ms Lori Michelson, 10/02/2004, Children's Institute, UCT, Ms Meryl Glaser, 13/02/2004, UCT, Healthcare 2010, 2002).

### Tertiary level care

A comprehensive speech therapy and audiological assessment service for children younger than 13 years is offered at Red Cross War Memorial Children's Hospital (RCCH) in Rondebosch, near Cape Town. Groote Schuur Hospital in Observatory, and Tygerberg Hospital in Bellville, 5 km and 20 km from Cape Town respectively, accept appropriate referrals of older children and adults from primary and secondary services within their drainage areas. They offer ENT and Audiology assessment and intervention services. The Tygerberg Hospital Cochlear Implant Unit also offers a cochlear implant service.

#### *1.5.3.2 Integrated services for the deaf child*

The importance of developing a seamless service including health interventions, educational programmes and social service support, is stressed by several writers (Luterman, 1979, Deyo & Gelzer, 1991, Gregory, 1995, Nevins and Chute, 1996).

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<sup>9</sup> The HARK (Hearing Assessment and Rehabilitation Centre) Project was a mobile outreach assessment, diagnostic, treatment and referral service from the Child Health Unit, Red Cross Children's Hospital, in collaboration with the MCWH Programme. It provided increased access to these services during the three year duration of the project from 1991-2001. The project team also promoted awareness within the three rural regions of the need for services for children with hearing problems. (Child Health Unit, 1999, Personal communication Ms Leana Olivier, 9/02/2004, provincial coordinator for MCWH, Department of Health, and Ms Lori Michelson, 10/02/2004, Children's Institute, UCT).

The Carel du Toit Centre, based on the Tygerberg Hospital site provides an example of such as service: It is registered and subsidised by the Western Cape Department of Education as an educational facility, and receives additional financial support of a trust fund. The facility offers a comprehensive auditory-aural habilitation and education programme for deaf children from birth to school-going age. Parents commit to investing a significant amount of energy in the programme, which regards parental involvement as the cornerstone of effective implementation of the programme. The Centre closely collaborates with the cochlear implant programme at Tygerberg Hospital, both in the identification of children attending their programme and who might benefit from this intervention, and in the education of the child and the provision of parent and family support following implantation. The Centre also offers a comprehensive once weekly individual parent guidance programme for parents of all deaf children under 3 years of age. This service is offered by the programme's social worker. As part of the Centre's community outreach service, parents from outlying areas can access the parent guidance service for an onsite 2 week residential programme every three months. The primary aim of this Centre's programme is to assist children to acquire spoken language and to learn to use residual hearing and amplification in communication with others. The goal of the programme is to prepare and support children to attend mainstream schools where spoken language is the medium of instruction. (Telephonic communication, Ms Loretta du Preez, 13/02/2004, Principal, Carel du Toit Centre).

Currently, a much-needed, similar comprehensive, integrated, coordinated and seamless service is not available in the province for children who are sign language users or users of total communication (Personal communication, Mr Stephen Lombard, 23/01/2004, Ms Wilma Neuhoudt-Druchen, 09/02/2004).

## Two

### Literature Review

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*Peter drove me to the area where he grew up and, with justifiable pride, he pointed to the house his father had built by hand many years ago...His hand swept across the panorama of a large brick house surrounded by acres of rolling pastures, and he shook his head. "People would never think a deaf man could do that". Months later...Della described a May Day celebration when her mother had sewn dresses and vests for every girl and boy in Della's grade school class. Della looked straight at me and said, "That's the kind of thing that people need to know about our parents. They need to get beyond this idea of deaf people as helpless and broken".*

From: Paul Preston, 1994, *Mother Father Deaf*, pages 52-53)

#### 2.1 Deafness and disability

##### 2.1.1 Defining deafness

*Audiological deafness* describes the degree of hearing loss from a full range of hearing, which a child or adult is medically measured to demonstrate<sup>10</sup>. People with a normal range of hearing demonstrate an ability to detect sounds without technical assistance, within a decibel range of 0-120, for example, from the sound of rustling leaves, through to the painful sound of a nearby jet engine.

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<sup>10</sup> An audiometric assessment produces an audiogram which measures hearing loss by assessing (a) sensitivity to pitch or frequency (measured in cycles per second or Hertz) and (b) sensitivity to loudness or intensity (measured in decibels). Frequency measurements range from 125 Hertz (low pitched sound such as a truck motor) to 8000 Hertz (high pitched sound such as a whistle) (Meadows, 1980, pg 2). Intensity or loudness is measured in decibels with one decibel (dB) being the smallest difference in acoustic power that a human ear can detect. The quietest sound to be heard is measured as 0dB and the loudest 120dB. (Densham, 1995, pg 153).

The report of the informal working group on prevention of deafness and hearing impairment programme planning meeting, WHO, Geneva, 1991<sup>11</sup> (WHO, 1998, pg 4), recommends that “disabling hearing impairment in adults be defined as a permanent unaided hearing threshold for the better ear of 41dB...” and for children under 15 years, as “permanent unaided hearing threshold level for the better ear of 31db or greater...”. Meadows (1980, pg 3) notes that whispered speech takes place within the 20 to 30 decibel range, conversational speech within the 60-70 decibel range and that speech detection is easiest within the mid frequency range of 500, 1000 and 2000 Hertz.

Rodder and Grove, 1987 (Densham, 1995) defines hearing impairment as a “loss of hearing that is severe enough to produce disorders of communication requiring remedial or educational treatment”. Densham (1995) notes that children who are born deaf, or who lose their hearing before they acquire spoken language may have greater (verbal) communication difficulties than those who become deaf after they have developed spoken language.

Following audiological assessment, deaf people may be diagnosed as having various degrees of hearing loss (Densham, 1995):

*Mild hearing loss:* Regardless of age of onset, the person cannot detect sounds below the 21-40 decibel range, that is, hearing loss does not exceed 40dB. Such a person cannot, for example, clearly hear a normal speaking voice in an ordinary environment.

*Moderate hearing loss:* Regardless of age of onset, the person cannot detect sounds below the 41-55 decibel range, for example, he or she cannot hear a baby crying softly in the same room.

*Moderate to severe hearing loss:* Regardless of age of onset, the person cannot detect sounds below the 56-70 decibel range, for example, he or she may not clearly hear a vacuum cleaner or a dog barking in the same room.

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<sup>11</sup> adapted at the first informal consultation on future programme developments for the prevention of deafness and hearing impairment, WHO, Geneva, January 1997.

*Severe hearing loss:* The person has an average hearing loss from 71-95 dB, or those with greater loss acquired before age 18 months of age. Such a person, for example, would not hear loud music playing.

*Profound hearing loss:* The person is born with, or acquired before age 18 months, an average loss of 96 dB or greater. Such a person, for example, will not hear drums playing in a nearby band, or hear an aeroplane taking off when standing next to it.

Other variables may also influence the ability to detect sound, such as

*the nature of the damage to the hearing system, whether conductive or sensorineural.*<sup>12</sup>

*the type and quality of augmentation, be it older or new generation digital hearing aids or the fitting of a cochlear implant.*

*the degree of "interference" or background noise, such as being able to hear a person's voice in a quiet room, but not in a school classroom or meeting where other normal sounds of movement and interaction may interfere with hearing.*

All the children in this study were diagnosed via audiogram as being moderately to profoundly deaf.

The earlier a hearing problem is detected, the better, be it for remedial action to medically or surgically treat a medical condition causing hearing difficulty which can result in hearing loss, or to detect hearing loss or deafness and provide parents with the

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<sup>12</sup> *Conductive* impairment relates to interference with the passage of sound waves through the outer and middle ear. *Sensorineural* impairment relates to damage to the cochlea mechanism in the inner ear and/or to the auditory nerve. The former may benefit from surgery or hearing aids and tends to affect all or low notes and vowel perception. The latter is usually medically untreatable and only marginally helped with hearing aid amplification (as sounds remain distorted despite amplification). This tends to affect the detection of all tones or high tones and some consonants. (Densham, 1995, Nevins & Chute, 1996). In *mixed* hearing losses the problem occurs in both the outer and inner ear. *Central* hearing loss occurs

guidance and direction to obtain the best medical, audiological, language, psychosocial and educational support for their deaf child, as early as possible. (WHO, 1998, pg 11).

### **2.1.2 Defining disability**

The above description of deafness uses the deficit-based terminology of the biomedical model of disability, such as “hearing impairment, and “hearing loss” (Harris, 1995). Within this framework, disability is seen from an illness, or impairment (loss of function from the norm) perspective. This perspective emphasises screening for potential problems with hearing, assessing the extent of the problem, deriving a diagnosis, and working toward applying interventions which will cure or return the patient as far as possible, to “normal functioning”. This perspective tends to focus primarily on the medical and surgical management and habilitation aspects of the hearing loss, and adaptation within the home and school. Medical and habilitation services are important aspects of the service supports to be made available to the child and parents of the deaf child. There is a risk, however, for the deaf person to be disempowered by the tendency for health providers trained in the biomedical model, to relate to them mainly in terms of a sick role, or as an impaired person, dependent on the expertise of the service provider. There may be insufficient attention to supporting the service user and family to enable the (deaf) person to optimally participate in ordinary everyday life roles. (DPSA, 2000)

### **2.1.3 Defining disability in South Africa**

The disability lobby in South Africa advocates moving away from this deficit based perspective of disability. It is felt that this perspective encourages discriminatory attitudes which devalues and stigmatises disabled people, permitting a lesser emphasis on their right to equal access to the social resources available to able-bodied people.

Instead, they advocate for the use of the social model of disability which underpins the United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (White Paper on Integrated National Disability Strategy, 1997, Integrated

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because of damage to the nerves in the pathway to the brain or in the brain itself (National Information Centre on Deafness, 1991).

Provincial Disability Strategy, 2002). This model recognises that people with disability are, for the most part, not ill, nor to be unfavourably compared to people without disabilities. In contrast to the biomedical model which sees physical or mental impairment as central to disability, the social model emphasises that disability is not primarily due to impairment. Rather, society is organised and designed for ease of living and access to social resources by able-bodied persons. Access for people who are not able-bodied is overlooked or restricted. (DPSA, pp. 5-6, 2000).

This dominant social organisation builds into our social fabric the ability for able-bodied persons to see themselves as people who have mastery, efficacy and social worth. In contrast it provides disabled persons with limited, disabling social choices and opportunities: (Hayley, 1981, Manfredi 1993, Harris 1995). Their specific physical and mental abilities are not accounted for in available choices. This restricts the disabled person's opportunities for optimal social engagement, and reduces ability to experience him or herself as valued members of society, capable in all areas of personal choice.

Beazley and Moore (1995, pg 2), writing within the social model, note that "deaf children have hearing impairment, but other people enable or disable them and their families, depending on how they behave, and what values underpin their attitudes". They feel, for example, that assessment procedures that delay detection and intervention, prescriptive options for communication, education and other support services, professional failure to promote parental competence in child management, and attitudes which undermine family preferences and practices can all contribute to the disablement of deaf children and their families.

#### **2.1.4 Redefining deafness**

*Cultural Deafness* relates to the deaf person's sense of identity as a Deaf person. It involves the individual's identification of self as Deaf, the use of Sign Language as their native language, and a sense of belonging to a community of Deaf persons.

Taylor and Bishop (Pg 1, 1991) use the term "deaf" to include all people who are not able to hear. They reserve the term Deaf for those people who identify themselves as



members of a "linguistic minority group, a discrete cultural group who use Sign Language and identify themselves as members of a Deaf Community" by a process of personal choice and self-definition.

Higgins, 1980 (Densham, pg 87 1995) defines a Deaf Community as people who identify with the Deaf world and each other through shared experiences as a result of being deaf. Reagan, 1990 (Janesick and Moores, pg 50, 1992) identifies 6 key defining factors of a Deaf community. These are : linguistic differentiation (Sign Language), attitudinal deafness (identification with Deaf issues), historical awareness, behavioural norms, endogamous marriage patterns (Deaf marrying other Deaf in the following generation) and voluntary contact and organisational networking among the Deaf.

Beazley and Moore (1995) use 'deaf' for deaf children of hearing parents, to denote that they may be *potential* members of the Deaf community, but, as young children, are raised within a hearing family, and, most commonly, are exposed to hearing culture and perspectives.

Preston (1994) describes how, feeling alone in a foreign city, he identified himself as a hearing child born to Deaf parents to a group of Deaf strangers he saw signing in a road. He obtained immediate entry to this group. He, a hearing man, was accepted "as one of their own", demonstrating the complexity of the cultural issues attached to being hearing, deaf and Deaf.

#### **2.1.5 Redefining deafness in South Africa**

Until the early 1990's, the oral (teaching deaf children to speak) tradition was the dominant framework which South African Deaf were encouraged to embrace. (Smuts Pauw, 1996). In keeping with international trends, however, the past decade has seen the growth of a local Deaf lobby, driven almost exclusively by the Deaf. This lobby advocates for the recognition of the Deaf community as a minority language group which is heterogeneous, but with ties based on a shared language, Sign, a shared socio-historical background as Deaf persons, shared concerns about access to social political

and economic opportunities, and shared knowledge and participation in Deaf-specific social and cultural norms and activities.

As local Deaf strengthen their identity as individuals and as a cultural group, so too are their expectations of equal participation and access to opportunities and services strengthened. Service providers for the Deaf and their families are urged by this lobby to examine the appropriateness of services to their deaf clientele and to work toward meeting the expectations of the Deaf. In a help-seeking situation for deaf children, the service user and service provider should be seen as partners in mapping the way forward, with the health provider supporting the child and family to make informed choices.

#### **2.1.6 *Personal choice***

There are many sectors among the D/deaf, including deaf people who have been raised with hearing parents in a hearing neighbourhood, and attended hearing schools or schools for the deaf which promote oral communication, often with the express exclusion of teaching Sign Language. Some of these deaf people may choose to live within and identify themselves as part of the broader hearing community, and have little or no contact with Deaf people (Taylor and Bishop (1991, pg 1). Others have acculturated to the Deaf community, regard themselves as Deaf, and live in both "worlds". Henry Kisor, an American journalist who has been deaf since the age of three years, does not sign and regards himself as an oralist, communicating in spoken language and through lip-reading. He makes the point (Kisor, 1990, pg 7) that all deaf people should not be regarded as belonging to one overarching "deaf culture" and instead describes himself as 'a member of a minority within a minority, a deaf man, living within a hearing world, and a deaf man living outside the Deaf world. He emphasises the individual deaf person's right to choose his or her own cultural affiliations, and to not be ostracised for these choices by either the hearing or Deaf community.

## **2.2 Language and communication choices**

Approximately 1.6 million South African's use Sign Language as a first language, of whom approximately 400 000 people are profoundly deaf and 1.2 million are extremely hard of hearing (DEAFSA, 1995).

Most deaf people in South Africa have hearing parents, the majority of whom are not functional signers. Most deaf children attend schools where the spoken language is the prime language of instruction, and where children learn to sign from other Deaf children on playgrounds, or via contact with Deaf people at social activities. Only 14% of teachers of Deaf learners are able to sign, with varying degrees of proficiency (DEAFSA, 1995). DEAFSA (1995) also estimates that a third of Deaf adults in South Africa are functionally illiterate, and have had no formal education, while the *average* deaf school leaver may demonstrate the written language comprehension skills<sup>13</sup> of an eight year old.

### **2.2.1 Available options for language and communication**

#### **2.2.1.1 Manual communication**

This refers to all visual-spatial forms of communication relying on body, head and hand gestures (Marschark, 1993).

#### **2.2.1.2 Sign (Sign Language)**

This is a standardised, fully-fledged language with its own morphological, syntactical and semantic rules (Marschark, 1993, pg 31). It takes place in the visual-spatial mode, using hand shapes, facial expression, bodily gestures, intensity of gestures and location of the sign-construct relative to the signer's body. Sign structure may be similar in different countries, but the language is not universal, with several sign languages and dialects across the world. American (ASL) and British Sign Language (BSL) are the best known

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<sup>13</sup> Studies on sign-accessed, culturally appropriate assessment of comprehension skills were not found during this literature review.

international languages in South Africa. South African Sign Language is a language in its own right, with regional variations.

#### *2.2.1.3 Signed English*

Spoken English is accompanied by signs in signed English. Ideas are directly and precisely translated, word for word, using signs and finger spelling of the alphabet, retaining the syntax and grammatical structure of the spoken sentence.

#### *2.2.1.4 Oral communication*

This approach focuses on assisting the child to learn to use any residual hearing it may have, as early as possible, either amplified with hearing aids, or, in the case of sensorineural hearing loss, with cochlear implantation for direct stimulation of the auditory nerve. The child's individual hearing profile is assessed. This assessment provides the basis on which children are given intensive, professional training to produce understandable speech (communication training) and interpret the sounds they hear (hearing training), augmented by speech (lip) reading skills<sup>14</sup>. The role of the parent and family in continuing the child's learning programme at home is emphasised, and parents are given training in the correct procedures for maximising hearing training and the acquisition of speech at home. The quality of speech the deaf child will (or won't) achieve depends on many factors, including the degree of the child's hearing loss, the age when speech training is started, the type and benefit provided by amplification, amount of exposure to speech, and parent and family involvement in the child's hearing and communication programme (National Information Centre on Deafness, 1991, Gibbin, O'Donoghue & Nikolopoulos, 2003).

#### *2.2.1.5 Total communication*

This combines aural and oral methods (amplification, speech and hearing), lip reading and manual signs in communicating with the child. There are many combinations of these modes which may be called total communication.

2.2.2 Broadly, the **three main schools** of thought on communication choices are:

#### 2.2.2.1 *Oral communication*

The focus is to teach children to speak and to communicate with others using the spoken language. In its strictest form, parents and children are generally discouraged from using or being aided by gestures or manual signs as it is felt that this might distract the child from focusing on the more difficult task of speech and hearing training.

#### 2.2.2.2 *Sign (Sign Language) as the native language of the Deaf*

In its strictest form, this perspective would like Sign Language to be seen as the primary language of the Deaf, as a minority language group, and to have Sign Language, the most accessible language for the Deaf, available to all deaf children and adults.

#### 2.2.2.3 *Bilingualism*

This approach advocates for teaching both Sign language as a fully-fledged language, and, to the child's ability, teaching Spoken Language as a fully-fledged means of communication with hearing people.

### 2.2.3 **Cochlear implants**

Cochlear implantation is currently aimed at "enabling profoundly deaf individuals to gain a sense of hearing and to develop and maintain spoken language skills" (Nikolopoulos, Archbold & McCormick, 2003).

Advances in cochlear implantation technology and the potential for successful outcomes have grown enormously, particularly in the last 10 years, relative to the communication gains it provided to clients in the 1980s. Although performance still remains variable, improvement and refinement of design, clinical procedures and aftercare support programmes for cochlear implantation have resulted in progressively improved

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<sup>14</sup> As only 30% of English sounds are detectable on the lips, deaf people will have difficulty relying on this alone to follow a line of communication (National Information Centre on Deafness, 1991).

communication outcomes for carefully selected clients fitted with these implants (Perold, 1999, Nikolopoulos, Archbold & McCormick, 2003). These advances have also widened the range of people deemed suitable for successful intervention<sup>15</sup>. The field is still comparatively young, and researchers and clinicians in the field acknowledge the need for further intensive work to identify or refine core areas for attention to further advance positive gains made thus far (Nikolopoulos, Archbold & McCormick, 2003). At present, it should be understood that the technology does not provide users with a normal range or quality of hearing.

Cochlear implantation raises many socio-economic, psychosocial and ethical issues which ongoing local research should inform, including:

- parental desire for access to the technology and programme support for their child, relative to their ability to commit to active involvement and follow-through with the essential clinical, home- and school -based interventions after implantation,
- the impact on the child's future options and pathways, of the family's "eligibility" for inclusion in a cochlear implantation programme,
- (un)realistic parental expectations of the process, time required and potential outcomes of the procedures for improving their child's communication skills. These expectations impact on parent-child relationships, and the child's development<sup>16</sup>,
- funding considerations regarding the availability of resources to fund this still-expensive technology. Extensive interdisciplinary professional follow-up and support of families is required. Professional support includes, for example, audiologists, speech pathologists, psychologists and educators. Given that the vast majority of (deaf) health-care users in South Africa do not have private

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<sup>15</sup> Inclusion criteria originally targeted children with little to no residual hearing in the 1980s, but evidence in the past decade that these children may perform better than hearing aided- children with more residual hearing, has led to implantation of children with more residual hearing, to provide them with greater opportunity for the production of intelligible speech, and improved communication. However, more recent advances in (digital processing) hearing aid technology also show gains for children with profound hearing loss. This calls for new comparative research of the efficacy of the two technologies for communication outcomes for children, and careful consideration in selection of candidates for cochlear implantation (McCormick, 2003).

<sup>16</sup> More information on factors influencing the expectations of mothers of children with cochlear implants in the South African context, and supports which may be offered to ensure realistic expectations, can be obtained from the work of Perold (1999), as this is beyond the scope of this dissertation.

medical resources, this would be of particular concern in local public sector health care settings where the principle of equal access to quality care is strongly dependent on the ability of the public health care purse to accommodate to resources needed for consistent provision of that care, and

- the grown child's later evaluation of the choices made for him or her by family and professionals.

#### **2.2.4 *D/deaf perspectives on language choice for the deaf child***

An approach which is overly reliant on teaching children to talk, or enhancing residual hearing to "normalise" the child, to the exclusion of Sign Language as a legitimate and accessible language for the child to learn, may be viewed as strongly dismissive of Deaf language and Deaf culture by some within the Deaf Community. This lobby might encourage training to optimise residual hearing and speech training, but not at the expense of Sign acquisition, nor in the context of "rectifying" or fixing the child's deafness. In the Western Cape, this sector of the local Deaf community would advocate for the social model of understanding issues related to Deafness, Deaf Culture and empowerment.<sup>17</sup>

Concern has also been raised by some within the Deaf community, about the impact, value, and appropriateness of cochlear implantation, a fairly new technology, for the overall development of the child as a d/Deaf person: Some sectors within this community have expressed grave concerns about the ethical appropriateness of invasive surgery on young children who are not sick, and note the potential for further stigmatisation of Deaf persons as impaired, by the introduction of new medical interventions to "cure" deafness, as opposed to investing time and resources in the inclusion and enablement of deaf persons in the community. Others note the right of parents to exercise informed choices

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<sup>17</sup> Deaf South Africa (DEAFSA) was established in the early 1990s and is affiliated to the World Federation of the Deaf (WFD). It is a Deaf-driven, national, non-profit organisation (NPO) advocating for Deaf rights, inclusion and access for the Deaf, including the right to have Sign language acknowledged as their first language. It has branches in each of the nine provinces, which link into national initiatives and address regional issues for provincial Deaf. Other hearing and deaf led provincial initiatives also lobby for deaf interests and provide services at local levels, some as affiliate members of DEAFSA. In the Western Cape Province, the Deaf Community of Cape Town (DCCT), a Deaf-run NPO, provides support services for the Deaf and their families in the province, particularly in the Metropolitan region. An assessment clinic, audiology services, sign language classes and a support service for parents is available.

for their children and have expressed concern about the need to avoid discrimination of cochlear-implanted deaf children within the Deaf community itself (Nevins & Chute, 1996). The latter point has particular significance for Deaf parents of deaf children who may be considering implantation for their deaf child or children (Gibbin, O'Donoghue & Nikolopoulous, 2003).

### **2.2.5 *The oral perspective on language choice for the deaf child***

The aim is to equip the child to use spoken language as it is felt that this would best equip the child to fit into mainstream life, and to have full access to the opportunities it presents. Deaf cultural issues and the acquisition of Sign has generally not been accommodated within this approach, with the focus being on promoting the child's integration into a hearing world. (Densham 1995, Beazley and Moore, 1995).

Adult deaf raised within the oral tradition may not identify with Deaf cultural issues or feel the need to acquire Sign Language to improve their lifestyle. Kisor (1990, pg 9) an oralist who has no residual hearing, gently advocates for avoidance of a one-size- fits-all approach, noting that "sign language is best for some, lip-reading and speech for others, and a combination of the two the most sensible compromise for many."

### **2.3 Parental responses to deafness**

Beaurain (1996. p.10) and Levitz (1991, p.13) note that it is not audiometric deafness per se which affects the child's development as a person, or results in developmental difficulties, but the context within which the child comes to experience him or herself as a (d/Deaf) person. Within the family, the primary context within which children come to know themselves, there is a significant relationship between parental attitudes toward their deaf children and the emotional adjustment of these children : Spencer and Deyo's (1993) and Beaurain's (1996), brief reviews of literature on deaf children born to Deaf parents suggest that deaf children develop appropriate language (Sign Language) and social skills, and are well adjusted within their family setting. Beaurain (1996) proposes that normal development of these children may be promoted by their parents' ready



acceptance of their children and ability to bond with their child. Through accessible communication channels, and within the familiar and positive framework of Deaf cultural and social supports, deaf parents may "join" socially and emotionally with their children in ways facilitative of their relationship and of the child's development (Spencer and Deyo, 1993).

This process may be interrupted in families with hearing parents of deaf children. Approximately 90% of deaf children's parents are hearing (Marschark, 1993, Spencer & Deyo, 1993). The vast majority of these parents are unfamiliar with deafness or Deaf language and culture. They will most likely only have their own hearing experiences on which to draw in understanding and processing the fact that their child is deaf. Several writers suggest that hearing parents may experience shock, confusion, grief, guilt, anger and feelings of inadequacy on discovering that their child is deaf (Luterman, 1979, Meadow, 1980, Deyo & Gelzer, 1991, Marschark 1993, Beaurain, 1996, Perold, 1999). Being able to hear is a basic unspoken point of reference for them in deciding on their child's overall wellness and potential for successful social integration. Deyo & Gelzer (1991) note that parents vary in the time taken and extent to which they come to terms with, accept, adapt to and cope with their child's deafness. Acceptance and adaptation is not a once off, linear process for parents, but may be an ongoing process, as new issues arise with each stage of the child's development, and as unspoken parental expectations are challenged.

Beazley & Moore (1995) acknowledge that parents may need time to adjust to the news that the child is deaf. However, they reject the tendency for professionals to work from the assumption that parents will invariably react with shock and grief because of the child's deafness and the loss of a "well child". They feel that this explanation locates the reason for this reaction solely within the individual psychological make-up of the parent. This might blunt professional attention to service and systemic issues which create barriers to parental adjustment. It might reduce professional responsibility for examining the appropriateness and adequacy of service supports for these parents. Insufficient attention may be given to devising innovative and parent- focused service supports which reduce barriers to parents' coping with their children. the point made is that social and other environmental factors may also contribute toward the impact of deafness on

parent's ability to cope with the child's developmental needs. Beazley and Moore (1995) and Gregory (1995) report a significant link between parental ability to cope with a diagnosis of deafness and its subsequent relationship implications, and the approach, beliefs and practices of service providers who break the news of their child's deafness and provide supportive services to the family.

Hewson (1997) also questions the inevitability of parents necessarily going through a set series of loss, grief or bereavement responses at the news of their child's loss of ability.<sup>18</sup> She notes that parents of children with disabilities may show similar emotional responses, but suggests that the triggers and functions of responses may be different for parents whose child has a lifelong disability, than for someone who has lost a loved one and needs to reorganise their lives to move on without this person. She also cautions against the assumptions that parents *must* show evidence of these emotional reactions to be able to adjust to the child's disability. She questions the view that their reactions are potentially pathological and in need of "working through" (pg 1129), and that parents who continue to evidence some of these emotions over a prolonged period may not have come to terms with the psychological "death of the idealised child" and accepted the child with his or her disability (pg 1131). Instead she proposes that parents' ongoing emotional reactions may be adaptive, and facilitate problem solving in parents ongoing work of adjusting to the child's needs. Hewson (1997) succinctly summarises her model as follows (pg 1137):

The Episodic Stress Model...highlights that recurrent episodes of stress are to be expected in the lives of people living with the loss of ability. These episodes can be plotted on a timeline which depicts both primary episodes (major crisis such as diagnosis) and secondary episodes (accumulated hassles and triggers). Different types of demands (comfort, stress reduction, recognition and adjustment) are made by stress at different times. The professional's task is to normalise the process, using education, preparation and counselling, and to

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<sup>18</sup> Hewson (1997) briefly reviews the well-known work of Kubler-Ross (1969), Bowlby (1980) and others on the sequential stages of emotional healing which can be expected following the loss or death of a loved one. Kubler Ross proposes 5 stages namely shock and denial, anger, bargaining, depression and acceptance, while Bowlby proposes four stages, namely numbness, searching, despair and reorganisation.

facilitate the client's attempts to address these demands in the way that works best for them.

### **2.3.1 Parent –child support**

Parenting the deaf child is both the same and different from parenting a hearing child. It is the same in the sense that children have universal needs and parents have to learn to make adjustments to their own and family life when a child arrives. It is different in the sense that deafness bring additional demands on the parent to access appropriate resources to meet some of their deaf child's needs (The National Deaf Children's Society, 2003). Parents are simultaneously the expert-in-progress on how to work toward meeting these needs, as they know their child best, and in need of the expertise of others to plot the most workable way to get there. Deyo & Gelzer (1991) and Beazley and Moore (1998) suggest that parents actively develop a support network of enabling professionals, other parents and families experienced in having deaf children in the family, and any community resource able to support them. The experience of parents of children with disabilities in addition to deafness may also be qualitatively different to that of parents of hearing or deaf-only children, with corresponding increases in the intensity and range of supports needed (The National Deaf Children's Society, 2003).

### **2.3.2 Supporting parent-child communication**

Hearing parents report that communication difficulties are often a key challenge to coping with raising their deaf child (National information Centre, 1991, Gregory 1995).

Parents' response to the "baby talk" of the young infant, and the little child's responsive expressions and body movements, helps to strengthen emotional bonds and to finely attune parent and child's responsiveness to each other (Stern, 1985, Marschark, 1993, Richter, 2001). Marschark (1993) notes that hearing parents may become disheartened by their deaf child's seeming lack of appropriate reciprocity to their - primarily vocal - interactions. They may feel rejected by their infants and undermined as parents. Beaurain (1996) postulate that the parental "helplessness" which may arise from this early communicative - interactional mis-reciprocity, may adversely affect parental

emotional bonds to their children. Manfredi (1993) points out that while hearing newborns and young children can use auditory cues to “track” and be soothed by the presence of others, and hear distant or approaching responses to their cries, the young deaf child is cut off from their caregiver when the caregiver is out of the child's visual field.

In line with the view that these observations should not be pathologised, but rather, that appropriate alternative coping strategies should be introduced to the parental repertoire, studies reviewed by Marschark (1993) focus on the positive outcomes of parental touch for deaf babies and young children. They suggest that teaching parents to replace (or augment) verbal responses to the baby with appropriately-timed soothing, rhythmic, and predictable nonverbal cues, such as facial expressions, gestures and touching (rocking, tapping, massaging, holding, etc). Similarly, teaching parents to look for and respond to the non verbal cues from the baby, can have a positive impact on the parent-child emotional bonding.

Mather, 1987 (Moore & Meadow-Orlan, 1990) reviewed the use of gaze by teachers who are native sign language users. These teachers use gaze to direct, pace and encourage communication with an individual or group of children. Deaf mothers and teachers who are native sign language users instinctively use a baby's visual field differentially to encourage and maintain the child's interest in maternal or teacher interactions. The variable pace, type and placement of a deaf mother's hands on the infant's body during communication with the baby are used in a similar way. Mather proposes that new visual and tactile communication styles can be taught to hearing mothers to increase positive interaction with their babies, both to benefit the parent-child relationship, and to encourage interactive communication development in the baby. Manfredi's (1993) findings also point to the need to alert parents to innovative ways to maintain the visual (or vibrational) contact field with the young child during daily activity. Early successes with the child make for more confident, relaxed parents. Struggling and frustrated parents can benefit from alternative, positive ways of relating to their child. Deaf-friendly ways of relating to their child can have positive outcomes for the child's as it develops a sense of itself, and negotiates other relationships beyond the home (Marschark 1993, Sameroff, 1993, Gregory, 1995, Beazley & Moore, 1995).

### **2.3.3 *Communication and the child's sense of self***

Communication is the primary vehicle for self-expression, social exchange and interpersonal validation as we develop as social and psychological beings. Barriers to language acquisition adversely impact on a child's access to social interaction in the family, neighbourhood, school and at play. It circumscribes the child's pool of knowledge about the world, and its ability to conduct the internal dialogue necessary to ascribe meaning, differentiate choices, and plan deductively as it engages with the world. Stokoe (1993) and Marschark (1993), in a review of literature of studies on deafness, emphasise that language is not speech. Marschark (1993) notes that a visual language such as Sign Language can effectively promote language development as it provides the parent and child with a common mode of communication.

Marschark (1993) points out that accessible language is generally introduced at a much later stage for most deaf children, than for hearing children. This may expose most deaf children to more potential difficulties in language, social and cognitive development than children acquiring language from an earlier age. Children who have had cochlear implantations at a younger age show better speech and language skills than older deaf children (Perold, 1999, Muller & Wagenfeld, 2003, Nikolopoulos, Archbold & McCormick, 2003). Those in favour of this procedure urge for the improvement of screening and earlier detection of hearing loss in infants and young children who may be suitable candidates for this intervention (Nikolopoulos, Archbold & McCormick, 2003).

Caution should be exercised in making statements about the potential negative impact of language and social difficulties which the deaf child may experience within the family setting. Marschark (1993) points out that social, emotional, cognitive and communicative development are interactive, and cautions against the blanket assumption that difficulties in specific areas, will necessarily compromise overall psychosocial well-being and development in Deaf persons. Children also bring their personal strengths and resilience which impact on their social experience, and which may act as protective factors in adverse situations (Sameroff, 1993, Zeanah, et al, 1997). Marschark (1993) notes that where differences in cognition, language and social

interaction are observed between deaf and hearing children, these should not be viewed as a consequence of deficits in the deaf children, but can instead provide insights to deaf experience which can inform the development of strategies best suited to the needs of deaf children and their families.

#### **2.3.4 *Communication, cognitive and social development***

Marschark (1993) reviews studies which show that deaf preschoolers tend to lag behind in using formal language in interactions with other preschoolers. They engage in play with multiple friends and interact with teachers less often than more verbal deaf or hearing children. On the other hand, they tend to use nonverbal, manual communication to converse with their peers, and their quality of friendships and play behaviour with other deaf and hearing preschoolers develop similarly to their hearing peers. The kind of play demonstrated by the deaf child with these friends tended to be contingent on the child's language ability, with more language enabled children showing more imaginative, complex and symbolic play than children whose language skills were more limited. Spencer and Deyo (1993) note that language delays and social development disruptions experienced by deaf children, not deafness per se, may negatively impact on the observed complexity of the child's play, and cautions against making direct inferences about cognitive *potential* from observing the maturity of the child's play, based on comparisons with hearing children. They suggest that further studies regarding the association of the development of play, cognitive and social skills, and the degree to which one can be taken to be a measure of the other should be done with deaf children themselves, rather than only via comparative studies with hearing children.

#### **2.3.5 *Assisting parents to assess options for communication***

Beazley and Moore (1998, pg 37) feel the most immediate need is to "get communication going" in the home to support the parent-child-family relationship, and to provide the child with the easiest access to teaching about the family. Communication choices for the deaf child are a hotly debated issue, politically, sociologically and clinically (Winefield, 1987). Parents of deaf children can become caught in the web of perspectives on what is "best" for the deaf child. Providing parents with information on available choices without facilitating the processing of this information until parents are

comfortable to make decisions on how to proceed, presenting one “best option” as a *fait accompli*, or providing confusing information to parents, can all contribute to the disablement of the parents and children. Professionals should equip themselves with sufficient information to assist parents to make communication decisions best suited to their circumstances, and to source available resources to actualise that choice (Deyo & Gelzer (1991).

## **2.4 Services for deaf children and their parents**

### **2.4.1 Screening and assessment**

Several screening tools have been developed to test hearing loss, and include:

- Behaviour-based methods using distraction tests such as the high frequency rattle <sup>19</sup> (where young children turn their heads in response to a sound) or performance tests (where the child waits for a sound and then responds as instructed).
- Objective tests which rely on the measurement of sound pressure levels in the ear in response to sounds, or computer analysed electrical responses to activation of the cochlear, auditory nerve and cerebral cortex (Densham, 1995, pg 164-167).<sup>20</sup>

### **2.4.2 Diagnosis of deafness**

Meadow (1980) notes that this may be significantly delayed due to the fact that, unlike other physical impairments, deafness can be “hidden” in other explanations of behaviour the parents may observe. The child may be labeled inattentive or naughty, the parents may suspect slow development or be confused by the child’s different reactions to different sound environments. The health practitioner, too, may disregard parental concerns in favour of a cursory “test” in the consulting room, which may produces a false

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<sup>19</sup> The rattle is no longer part of the screening protocol in the WCP, but there are anecdotal reports of staff still using the rattle in clinics, despite training in the use of the new screening protocol (Personal communication, Ms Leana Olivier, 9/02/2004

<sup>20</sup> These tests are as yet not widely available for use as part of the local public service programme due to cost constraints.

result. Anxious parents can also more easily 'ignore' their suspicions than if the child had a more visible impairment.

#### **2.4.3 *Medical and surgical Interventions***

In some instances medical procedures can be used to treat or correct physiological problems which may result in hearing loss. In others, surgical procedures, such as cochlear implantation may be used to augment available hearing.

#### **2.4.4 *Psychological interventions: The emotional development of the child***

There is insufficient attempt to locate interventions within the context of the child's social and emotional development. This occurs despite extensive literature on the importance of secure, reciprocal parent-child relationships for the child's development. These relationships underpin parental ability and emotional availability to facilitate the child's development, and enhance the child's ability to respond to parental overtures (Ainsworth, 1978; Stern, 1985, Bowlby, 1988, Stern 1998, Richter 2001).

#### **2.4.5 *Parental inclusion in treatment/intervention.***

Review of early intervention programmes has shown that the long-term effectiveness of interventions is better when parental involvement is a central part of the programme. Parents have indepth knowledge of the child and the ability to provide insights which can improve interventions suggested by professionals. Parents are expected to be co-workers in implementing home-based interventions, and need accessible educational input to assist them to understand and manage their child's needs (Luterman, 1979, Stahlecker, 1983, Deyo and Gelzer, 1991, The National Deaf Children's Society, 2003).

#### **2.4.6 *Schooling***

Education options include placement in schools for children with special needs (schools for deaf learners) or integrated into mainstream classes (WHO, 1998, pg 11). Deaf children as young as three years may be placed within school hostels, particularly when



families live great distances from available schools. Many children only have contact with their families during school holidays.

South African deaf children are almost exclusively taught by hearing teachers. There is little or no attention to raising awareness among these children of issues related to Deaf and hearing culture as part of their education. Janesick and Moores (1992) note the role that education plays in carrying over cultural knowledge and perspectives. Schools are a microcosm of broader society, have a culture of their own, hearing or Deaf, to which the child is exposed and against which the child comes to measure itself, enabled or disabled, as the case may be.

Nevins and Chute (1996) emphasise the importance of well-established links between health services and educational institutions attended by deaf children. This is important to ensure a smooth transition for the child and family, to an environment where the available communication strategies support those which have been started at home, or within the health sector.

## **Three**

### **Research Design**

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#### **3.1 Theoretical influences**

##### **3.1.1 Personal and professional experience**

The past few decades have seen a growing movement in research away from relying on professional expertise as the central driver, to the inclusion of the users of research in developing research agenda (Hall, 1981). In health research, there is a greater emphasis on the interface between professional knowledge, and client choices and satisfaction with healthcare provision (Marsh, 2000). Research users are more actively engaged in research recommendations for policy and programme development, treatment, recovery and (re)habilitation. This trend is fully supported by the researcher. She has worked as a clinical psychologist in the fields of substance abuse, mental disability and intellectual disability for approximately 20 years, first as a clinician and later as a mental health policy and programme developer in the public health service. During this time she has observed the stigma, barriers to care and lack of consultation in service development regularly faced by persons with disabling or socially unacceptable health conditions. Her experiences of voluntary community work for a local residential home for Deaf adults in the past 10 years has further supported her observations of the barriers to access and sub-optimal satisfaction of persons with disabilities using public health care.

##### **3.1.2 Assumptions**

These professional and personal experiences have shaped the researcher's perspective on best practice as a researcher in the field of disability. An *advocacy/participatory perspective* to research has influenced the conceptualisation, design, analysis and reporting of the current study. This perspective holds that research should inform the

empowerment of marginalized people such as persons with disabilities. It should offer an agenda for change which may enhance their quality of life and participation in society (Creswell, 2003). Research in the field of disability should focus on enabling persons with disabilities to reach their optimal level of independent functioning in the community. At the micro level, research should aim to help overcome barriers to optimal functioning within individuals and their social environments, as well as promoting the development of competencies within clients and their support systems (Farkas, Anthony and Cohen, 1989). At the macro level, research should advocate for the placement of the client's perspective and goals as the starting point of work with persons with disabilities (WHO, 1996). In the health sector, the outcomes of such research could assist health practitioners trained within the traditional medical model to better understand and work within the empowerment approach to health care advocated by the disability sector and by the Deaf lobby, as described in the literature review.

### 3.1.3 Strategies of inquiry

An agenda for change can best be framed if the researcher's grasp of the core issues has been enhanced by an in-depth understanding of the issue under investigation, as experienced by participants. A central purpose of this study is to understand hearing parents' experiences of raising a child who is deaf. The study emphasises their experiences of the health services used for their child. These experiences are used to make inferences about service needs of parents, and these needs inform recommendations regarding required service provision.

A single paradigm is insufficient for analysis of the above processes. A *phenomenological approach* frames and guides the narrative inquiry, while a *pragmatic approach* informs the transition from this experiential endeavour to a substantive action plan to address the needs highlighted by this inquiry. Phenomenological inquiry seeks to identify and describe, as far as possible, the "essence of lived experience" of people relative to a certain phenomenon, and to intuit the meanings of these experiences for these individuals (Mayan, 2001, pg. 9; Creswell, 2003, pg 15). The pragmatic approach emphasises the identification of problems and sourcing of solutions using a pluralistic approach to understand a given problem (Creswell, 2003). Within this inter-paradigmatic

framework of inquiry, experiences provide a useful source of information from which to infer what supports parents need, and to make recommendations for improving services to enhance parenting (Hudelson, 1996, Creswell 2003).

#### **3.1.4 Selection of research methods**

In this study, parents' attitudes, beliefs and subjective experiences are a core source of data to address the research questions and related objectives. Qualitative methods, such as unstructured interviewing, are well suited to identifying and describing the experiential issues and processes which is the focus of this study (Gergen, 1988; Mitchell & Jolley, 1996; van der Merwe, 1996; Hudelson, 1996; Mayan, 2001; Creswell, 2003). Interviewing allows the researcher to pursue a detailed exploration of parents' experiences, with qualitative analysis providing an appropriate means of deriving meaningful interpretations of the text collected during these interviews (Hudelson, 1996; Schurink, 1998; Mayan, 2001). Given the potentially distressing nature of the issues to be dealt with by the study, interviewing also provides an opportunity for supportive containment of any emotional discomfort which might arise as parents' personal accounts unfold (Meadows-Orlan, 1990, pg 321).

#### **3.1.5 The role of the researcher**

Creswell (2003, pg 182) notes that " the personal-self becomes inseparable from the researcher-self". The researcher's personal experience with deaf issues, her clinical work in the fields of mental and intellectual disability, as well as her work as a policy and programme developer in the public health service, have undoubtedly influenced this study's process, the findings and the generation of solutions to the problems raised by parents. Her psychological training influenced her interrogation and interpretation of the data. This training provides the core skills of unpacking subtle meanings in narrative data and of "bracketing (her) own experience in order to understand those of participants", which is so central to phenomenological inquiry (Creswell, 2003, pg 15). Her discussion of these findings is informed by her experience as a psychologist and a health worker in the public health sector. Her policy and programme development experience in this sector provides the context for recommendations.

While these experiences and knowledge base provide useful insights from which to understand and utilise the research findings, the researcher's personal biases may also constrain the perspectives which are made explicit in the study report. Methods of curtailing this bias are elucidated below.

The researcher was a practitioner in another clinic on the same site as the clinic used for this study. This facilitated access to and understanding of the work of the clinic. Clients' understood that the researcher worked at another clinic related to the site they attended and this seemed to enhance their comfort in agreeing to participate in the study. However, the researcher's role as a service provider at a "sister" site might have constrained parents' levels of comfort in being entirely frank about their experience of the service.

## **3.2 Methodology**

### **3.2.1 Ethical considerations**

As a staff member of the Red Cross Children's Hospital, Child and Family Unit at the time of the data collection, the researcher was bound by institutional confidentiality provisions when accessing client records to identify prospective participants.<sup>21</sup>

### **3.2.2 Selection of participants**

Children who screen positive for hearing loss at clinics are referred for more specialised care to Red Cross Children's Hospital (RCCH) in Cape Town, if primary level intervention is not successful. Children diagnosed as deaf at RCCH were subsequently referred for further assessment and intervention to the RCCH Deaf Child Clinic based within its Developmental Clinic<sup>22</sup>. The study population of 20 children was drawn from parents and children referred to the Developmental Clinic.

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<sup>21</sup> The research proposal for this study was approved by the University of Cape Town Research Ethics Committee.

<sup>22</sup> The Deaf Child Clinic and its services has since been incorporated into the Audiology and Speech Therapy Services at RCCH.

The data collection methods selected for the study is labour intensive. The limited scope of this mini-dissertation and resource constraints to conduct and analyse the in-depth interviews, limited the sample size. Critical case sampling was used to select participants to maximise the range of information available from the small sample: Participants who had experienced all levels of service were ideal; hence the selection of a tertiary site, to which parents would have been referred from primary level services. Within this site, case selection was purposefully stratified to include only participants whose children had a definite diagnosis of deafness, within the moderate to profound range of deafness, and who were younger than 6 years of age. Clients whose children met these criteria were consecutively identified from the weekly clinic booking schedule and approached to participate in the study when they arrived for their appointment. The researcher outlined the broad objectives of the study to potential participants. They were informed that participation was entirely voluntary and that declining participation would not adversely affect the current service offered to their child. A copy of the informed consent form (Appendix Two) was discussed and signed by parents who agreed to participate. Two of 22 parents declined to participate due to time constraints. Participants included parents who spoke English (7), Afrikaans (8) or IsiXhosa (5).

### **3.2.3 Data collection**

A mixed methods approach advances the use of more than one method of collecting data, to reduce the bias inherent in any one method, and to provide the researcher with more than one lens from which to view the data collected (Creswell, 2003).

#### **3.2.3.1 Tools**

A semi-structured interview schedule (a) and a questionnaire (b) were used.

(a) The researcher constructed an *interview schedule* (Appendix Three) from literature reviewed on topics related to the set objectives (Moore & Meadow-Orlans, 1990, Levitz, 1991, Marshark, 1993, Beazley, & Moore, 1995, Gregory, 1995, RCCH Child and Family Interview Schedule, undated).

The interview schedule covered the following issues:

- (a) Biographical information
- (b) Development of child
- (c) Detection, help-seeking and diagnosis of deafness
- (d) Language and communication
- (e) Self-help and social skills
- (f) Management and discipline
- (g) Relationship issues
- (h) Future concerns
- (i) Guidance and Support

(b) The **questionnaire** (Appendix Five) used was designed by Meadow - Orlans (1990). The questionnaire consists of 3 sections, namely (1) demographic information, (2) family characteristics and (3) impact of hearing loss on the family. Section 3 consists of 24 questions designed to assess the impact of a child's hearing loss on the family in 5 domains. The five domains are:

- (a) effect of the child's deafness on family members,
- (b) parental concerns re communication difficulties,
- (c) parent relationships with professionals,
- (d) parental satisfaction with the child's progress and
- (e) the treatment of the child by others in the environment.

These domains are represented in 3 scales measuring:

- Stress (8 Items from (a), (d))
- Communication (8 Items from (b), (d))
- Relationships (8 Items from (c), (e), (d))

Participants were required to select one of 4 response categories to each of the 24 items, namely strongly agree, agree, disagree and strongly disagree. The researcher assigned a value of 1 – 4 to each of the 4 responses categories to indicate parental opinions which were strongly positive (Score 1), positive (Score 2), negative (Score 3) or strongly negative (Score 4).

Meadow-Orlans (1990) compiled this questionnaire following extensive interviewing with parents, and piloting and refinement of the instrument. It was selected for this study as it provided a structured measure of key aspects covered by the unstructured interview schedule. Specifically, it provided an indication of the *extent* to which deafness has contributed to high stress levels of parents, difficulty in the area of communication and of the impact of key professional relationships to support parents with their deaf child. The questionnaire was translated into Afrikaans and IsiXhosa for use in this study.

### **3.2.3.2. Procedures**

Sixteen interviews were conducted with mothers only, two with mothers and the maternal grandmother, and two 2 interviews with both parents present.

Participants were interviewed for one or two sessions, using the *interview schedule* as a guideline. Interviewing continued until all areas of exploration was covered with each participant. The interviewer raised each area in the interview schedule, unless spontaneously mentioned by the parent, with parents allowed to direct the flow of information around this area according to personal experience. Interviews were audiotaped with the permission of participants. The *questionnaire* was administered at the end of each interviewing period. As the researcher is proficient in English and Afrikaans only, an interpreter working at RCCH was used when IsiXhosa- speaking parents (5) were interviewed.

Following the interviews, where parents had identified barriers to managing their child's deafness or a need for additional information, permission was requested for the researcher to contact the team working directly with the child at the Deaf Child Clinic. Team members were provided with brief input on difficulties, additional assistance or information required by parents. In most instances, parents welcomed this where concerns related specifically to the child's care plan.



### **3.3 Analysis of data**

A strategy based on Glaser and Strauss' (1967) "grounded theory" approach was used to analyse and interpret the textual data of the interviews (Poggenpoel, 1998, de Vos & van Zyl, 1998). Grounded theory uses a systematic set of inductive procedures to derive theory about a given phenomenon. It relies on researcher insight to the subtle meanings of the data, gained through concerted engagement with relevant literature, expert/informed opinion, and personal/professional experience about the area of inquiry. A systematic application of selected tools of analysis is used: Data is coded exhaustively, trends are identified and concepts or response categories elicited, while maintaining a skeptical attitude *vis a vis* the emerging concepts. These are revisited, inconsistencies and new leads noted and interrogated, and trends compared, in an effort to ground the theory in the core trends emerging from the material. (de Vos & van Zyl, 1998; Mayan 2001, Creswell, 2003). While the current study is less interested in developing theory *per se*, it is concerned with deriving a set of actions for improving the quality of life of participants which is grounded in an understanding of participants' experience.

#### **3.3.1 Biographical information**

Two detailed tables, focusing on child-related and parent- and family-related information respectively, were compiled from the biographical information obtained from parents. Each child was assigned a number from 1-20 in these tables. These numbers have been used as an identifying number throughout the analysis, in the headings of quotations and in the summary tables in the appendices. These detailed tables were used by the researcher as an easy reference for analysis of biographical data. The tables are not included in this report to protect the identity of parents and their children.

#### **3.3.2 Interview schedule**

The taped interviews were transcribed verbatim. The data was analysed by hand using a system of coding "segments of text in order to classify what is written...from ...key concepts and themes that emerged during the research" (Hudelson, 1996, pg. 56). The content of the interview schedule, the questionnaire and a preliminary reading of all the

transcripts was used to compile a theme sheet enumerating themes which were likely to emerge from the interviews (Hudelson, 1996; Creswell, 2003).

The interviewer and one other professional familiar with the study and experienced in deaf issues used the theme sheet to independently code the transcripts of two interviews according to the identified core themes. Interviews were analysed line by line to code themes raised by each parent. Provision was also made to code new themes which had not yet been identified on the theme sheet. This was done to assist with the refinement of the theme sheet and to ascertain whether the process of analysis of the study data would reasonably yield similar themes, if analysed by other researchers. The independent rating proved fairly compatible (90%), and with minor adjustments, the theme sheet was used by the researcher to code the text of the remaining interviews.

Files were created for each theme. The coded text related to each theme in each interview was catalogued in these files. Each coded segment was referenced with the child's name and assigned identifying number before allocation to the appropriate file. In this way, themes that were common to parents were grouped in the files into response categories. This method allowed the researcher to easily identify the strength of the theme (number of parents who had raised or responded to that theme) and to identify similar and dissimilar viewpoints within each theme. The study reports the most prevalent themes extracted from the transcripts. Appendix Four Contains (a) the theme sheet and (b) an example of coded text from an interview.

### **3.3.3 Questionnaire**

The questionnaire was used as an adjunct to the qualitative responses of participants, to indicate the extent to which deafness affected stress levels of parents, created difficulty in the area of communication, and impacted on relationships with professionals providing support to parents. Descriptive statistics were derived from this data.

### **3.4 Validity and reliability of the data**

#### **3.4.1 Internal validity**

It is difficult to gauge the extent to which the findings of qualitative studies aimed at documenting beliefs, attitudes and experiences accurately reflect these phenomena in the study population (Hudelson, 1996; Mayan 2001; Creswell, 2003). The researcher's own belief system, style of enquiry and prior professional training, participants' responses to these, the context within which the interviews take place, the comprehensiveness of the research tools, and method of analysing data are but a few factors which can shape the validity of the reported findings.

Viewing the research process and data from different perspectives can assist the researcher to more accurately conceptualise, collect, analyse and report on the scope and depth of the issues related to the situation under investigation (Hudelson 1996; Creswell, 2003). In this study, data was collected using both an interview schedule and a questionnaire to provide different sources of data. Nesting of one data source in another can assist in improving the internal validity of reported findings (Mayan, 2001; Creswell, 2003): The results and discussion synthesise data from all sources of information (literature, the questionnaire and interview findings).

#### **3.4.2 External validity**

External validity or generalisability of the findings of qualitative studies relate to the extent to which the study findings can be applied to other people or other contexts (Mayan, 2001). As the sample size and scope of the study is limited, findings may reflect themes pertinent only to this small group. Questionnaire results also provide descriptive statistics specific to the study group. The study therefore has limited generalisability. Nevertheless, it is felt that the results may provide valuable preliminary insights into the needs of parents who use hospital and clinic services, and highlight factors which need consideration in work with this population in the public health sector.

### 3.4.3. Reliability

Reliability is concerned with the extent to which the *same findings* will be obtained if the research strategy is repeated by the same or other researchers. The concept of reliability is not usefully applied to qualitative inquiry, as is the case with the *interviewing* process and interpretative analysis in this study, which focused on deriving *new perspectives* on the study topic (Hudelson, 1996 Mayan, 2001). The *questionnaire* used was applied to groups of parents from various socioeconomic strata and cultural backgrounds during its development, within an American setting. The study groups included parents of the age group targeted by this study, but was also applied to parents of older children. These studies met stringent test-retest reliability requirements (Meadows-Orlan, 1990)<sup>23</sup>. The raw data obtained from the questionnaire is presented in tables in the appendix, and the process of analysis and reporting of the data has been detailed.

## 3.5 Presentation of results

### 3.5.1 The Interview data

Chapter four reports biographical information of the study group, using pie charts and tables to summarise relevant data on the parents and their children. Subsequent chapters outline the main response categories or themes which were raised during the interviews by most parents, as follows:

- Chapter 5: Detection, help-seeking and diagnosis of deafness
- Chapter 6: Communicating with parents
- Chapter 7: Sources of stress for parents
- Chapter 8: Communicating with the child
- Chapter 9: Rearing the deaf child

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<sup>23</sup> Local parents had no difficulty understanding and responding to the simple questions. Question 18 on educational opportunities is better suited to older children, however, and the finding for this item is contextualised in 9.3 relative to the experience of the parents of the younger children participating in this study.

Verbatim quotes from the interviews are used in each chapter to illustrate parental viewpoints and to contextualise the summarised data (Hudelson, 1996). Where portions of the dialogue have been left out, this is indicated by three dots (...).

### **3.5.2 The questionnaire data**

The raw data and scale summaries for the questionnaires are reported fully in the appendix. Raw scores are listed in Appendices Six (a), (b) and (c), and further summarised in Appendix Seven.

In chapters 5-9 the summarised findings are linked to related themes raised in the interviews. A consistent format is used for the charts and tables reporting the findings for the three questionnaire scales. This permits easier comparison of the data within and across chapters.

## **3.6 Discussion and recommendations**

Chapter 10 provides a discussion of the results, while Chapter 11 outlines recommendations suggested by these results and potential areas for further research.

## Four

### Biographical Information

*My father had these gnarled old worker hands. And when he talked, his signing was kind of stiff and rugged, just like me. (Laughs.) And I never realised it until a few years ago, when someone said, "You, know, you sign just like your father."*

Informant quote: In Paul Preston, 1994, *Mother, Father, Deaf*, page 59.

#### 4.1 Child profile

Tables One and Two summarise biographical information on the 20 children.

Age in years	No.	%
1-2	3	15
2.1. -3	9	45
3.1-4	6	30
4.1-6	2	10

Sex	No.	%
Boys	10	50
Girls	10	50

Racial Designation <sup>24</sup>	No.	%
Black	5	25
Coloured	13	65
Indian	0	0
White	2	10

Degree of Deafness	No	%
Profound	6	30
Pending <sup>25</sup>	2	10
Severe	6	30
Moderate	6	30
Mild	0	0

Cause of Deafness	No	%
Heredity	1	5
Mat. rubella	2	10
Meningitis	1	5
Other Medical	5	25
Unknown	11	55

Additional Disabling Conditions	No	%
Intellectual Disability	2	15
Physical Disability	2	5
Int & Phys Disability	2	10
Suspected Intell Dis	(2)	(10)
None	12 (14)	60 (70)

<sup>24</sup> Racial classifications used under the previous administration in the country are used, as service access and equity in the current system is still impacted upon by previous racially -disparate socio-economic policy.

<sup>25</sup> Provisional diagnosis of Moderate to Severe hearing loss has been made

Table Two indicates the primary caregiver of the child.

**Table Two: Childcare arrangements**

Childcare	No.	%
Mother only	12	60
Mother and Maternal Grand Mother (MGM)	6	30
Mother/Father/Family	2	10

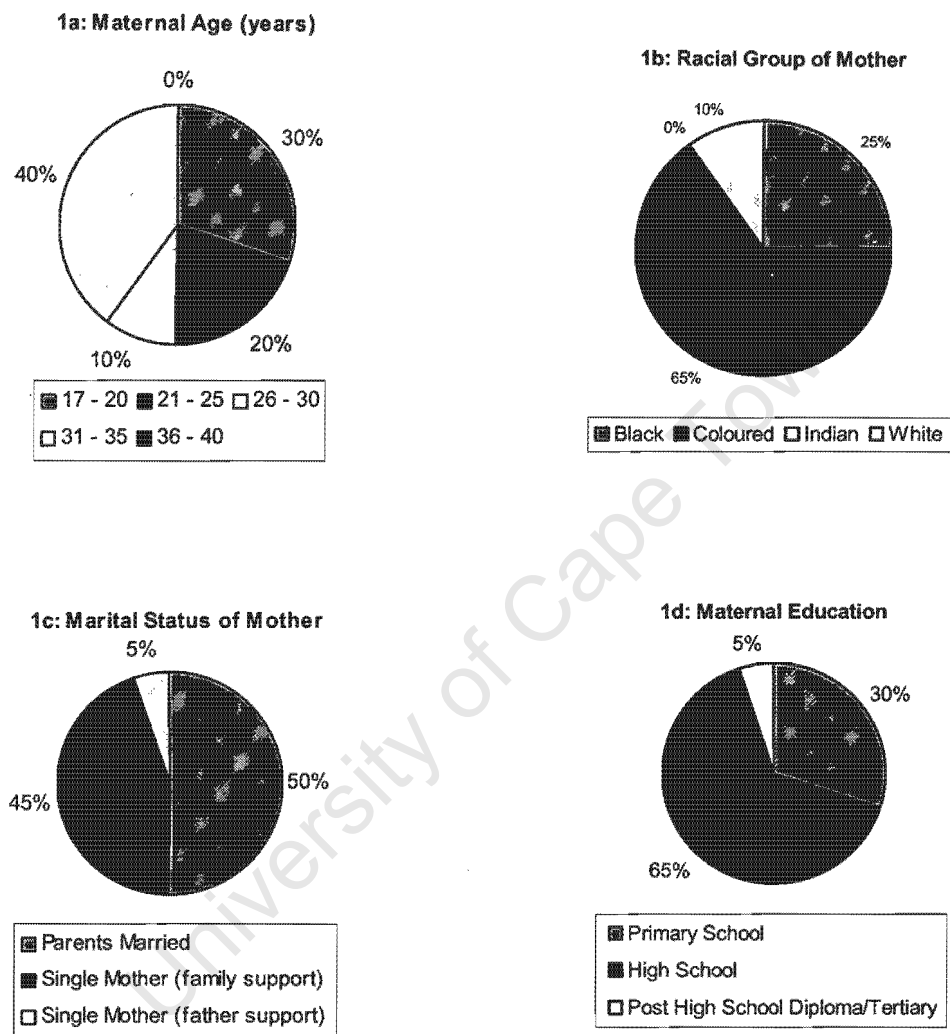
The children, 50% boys and 50% girls, ranged in age from 1 year 10 months to 5 years 8 months. Hearing loss ranged from moderate to profound, the cause of which was unknown in 60% of the children.

30% (6) of the children had additional disabling conditions resulting from medical disorders (liver cancer, brain tumour, muscular dystrophy, chromosomal disorder, microcephaly, developmental delay following foetal anoxia). Two more children were still to be assessed for suspected developmental delay as a result of maternal rubella. Two other children had older siblings with serious health problems unrelated to hearing problems.

#### **4.2 Maternal and family profile**

Figure One below summarises maternal age, education, ethnic background and relationship status.

**Figure One: Maternal characteristics**



Fifty percent (10) of the mothers were age 25 years and younger. Seven of this group were unmarried, two were living with their child's father and 1 was in a conflictual marriage. Eight were unemployed or working on a casual basis, living with and supported by their parents or grandmothers. One mother had fulltime employment as a cashier and the remaining mother was back at school. Three of these women were clinically depressed.

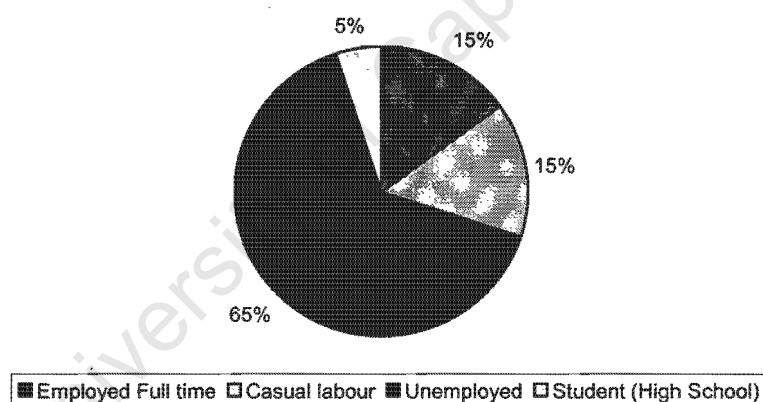


Ten percent (2) of the mothers were age 26-30 years. Both were unmarried, one working and one clinically depressed.

Forty percent (8) of mothers were age 31-35 years, seven of whom were married and one divorced. Seven of these mothers were unemployed housewives and one was working as a machinist in a factory. This group included two clinically depressed women, and two significantly stressed women.

Figure Two and Table Three below outlines maternal supports in terms of parental relationship status and family economic conditions.

**Figure Two: Maternal employment status**



The 20 parents interviewed were from working class families, with 50 % (10) having some income from formal employment, where either both or one parent was employed in low income jobs. 50% had no formal income, relying on occasional (casual) income (e.g. domestic work, hawking), or support from parents', or grandparents' pensions. Considering maternal employment, 3 mothers (15%) had permanent and 3 (15%) had periodic (casual) employment, and 13 mothers (65%) were completely unemployed. This larger group included 3 women at home as housewives by joint decision with their employed spouses, 3 mothers who had never worked, and 7 mothers who stopped working due to the high care needs of their deaf child.

**Table Three: Employment and income status of the family**

<b>Overall Income</b>	<b>No.</b>	<b>%</b>
Parents married, joint income, both work	2	10
Parents married father employed only	7	35
Single mother, employed	1	5
Single mother, unemployed, with maintenance from employed father	1	5
Parents married, both unemployed, no child care grant	1	5
Couple in relationship, living separately, both parents unemployed, no childcare grant or maintenance	1	5
Single mother, unemployed, absent father, no childcare grant	7	35

One couple (5%) was from an economically stable working class background. They were both high school educated, but earned low incomes as Technicon students supporting their studies with bursaries and casual waitressing. The remaining mothers (19) reported having had completed Grade 7 to Grade 10. One mother had matriculated, but most reported completing Grade 9. One mother (5%) had returned to high school after the birth of her baby, with support from her mother.

#### **4.3 Maternal mental health status**

The interview included questions on family mental health and substance abuse history, and parents were screened for mental health problems by the researcher, a registered clinical psychologist.

Table Four below summarises findings on maternal mental health status, maternal perceptions of the quality of the parental support in childcare, and of maternal coping with childcare.

**Table Four: Maternal mental health status**

Maternal Mental State	No.	%
Well, no diagnosis	12	60
Stressed, symptoms associated with depression, but no clinical diagnosis	2	10
Clinically depressed	6	30

Maternal perception of coping with child		Maternal Mental State (%)		
		Well (No clinical Symptoms)	Stressed (Some Symptoms)	Clinically Depressed
Coping	14	12 (60%)	0 (0)	2 (10)
Coping, Stressful adjustment	3	0 (0)	2 (10)	1 (5)
Not coping well	3	0	0	3 (15)
TOTAL	20	12	2	6

Observed maternal Interaction with child		Maternal Mental State ( %)		
		Well (No clinical Symptoms)	Stressed (Some Symptoms)	Clinically Depressed
Calm, Loving Caring, Firm Response	15	12 (60%)	1 (0)	2 (10)
Stressed, Caring, Firm Response	2	0 (0)	1 (5)	1 (5)
No or poor response to child	3	0 (0)	0	3 (15)
TOTAL	20	12	2	6

Maternal Perception of quality of paternal support		Maternal Mental State (%)		
		Well (No clinical Symptoms)	Stressed (Some Symptoms, no diagnosis)	Clinically Depressed
Good	7	6 (30%)	1 (5)	0 (0)
Conflictual	5	2 (10)	1 (5)	2 (10)
Absent	8	4 (20)	0 (0)	4 (20)
<b>TOTAL</b>	<b>20</b>	<b>12</b>	<b>2</b>	<b>6</b>

Twelve (60%) of the mothers were mentally well, with no current clinical mental health symptoms detected or reported during the interviews. These mothers reported having made a good adjustment to providing care for their children.

Six (30%) mothers were found to meet the DSM-1V criteria (American Psychiatric Association, 1994) for major depression and referred for further treatment to their local mental health clinic. One of these mothers, the youngest in the group at age 17 years, also had a history of substance abuse. Four of these six women reported having some difficulty in caring for their child's hearing related needs. Two depressed mothers reported coping well with childcare. Two (10%) mothers, although not clinically depressed, evidenced some symptoms associated with depression, and reported excessive stress in providing good care for their child. No other mental health disorders were detected during screening.

The small number of participants precludes definitive statements about adverse or promotative influencing factors in adjustment and coping of the women in the study, however the following trends were noted:

- All well women **reported** coping with their children, whereas there was a tendency for stressed or depressed women to report stressful adjustment to, or not coping with their children.
- All well women were **observed** to be calmly and caringly aware of their children and responsive to their needs, whereas the larger percentage (5 of 8) stressed and depressed mothers were more likely to relate to their children in a stressed manner, or be unresponsive to their children's' behaviour (requests for attention from their mothers, or disruptive behaviour were ignored, or there was little or no interaction between the mother and child).
- Well mothers perceptions of paternal support were fairly equally spread among the categories of good, conflictual and absent paternal support. Stressed and depressed mothers tended to report conflictual and absent paternal support. Three of the 6 depressed women reported divorce/severe marital problems as a major stressor in their lives.
- The 8 mothers who were clinically depressed or feeling stressed included:
  - 3 of the 6 parents who had children with confirmed additional disabling conditions,
  - Both mothers who had had rubella during pregnancy and whose children were awaiting assessment for intellectual disability.

Two other children had older siblings with serious health problems unrelated to hearing problems. One of these mothers reported difficulty in managing 2 children with disabilities (see example of transcript in Appendix Four).

This suggests that the following factors may increase the burden of care of mothers with deaf children:

- maternal depression, or other mental health problems
- marital/familial conflict
- additional disabling conditions beside the child's deafness and, possibly
- the secondary impact of the above factors on the development of positive interactions or bonding between mother and child, as the foundation of the development of self-esteem, self-regulation and pro-social behaviour in the child.

## Five

### Detection, Help-seeking and Diagnosis

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#### 5.1 Detection of deafness

Table Five summarises information related to:

- the detection of a potential hearing problem in the child,
- parents' experiences while seeking help for their child's problem and
- their experience while waiting for a diagnosis of their child's condition.

**Table Five: Detection, help-seeking and diagnosis of deafness**

Time period	Age at detection by parents or clinic staff	Lapse in time from detection to help-seeking by parents	Lapse in time from parent help-seeking or clinic detection to diagnosis
Under 1 month	0	13 (65%)	0
1 – 6 months	5 (25%)	4 (20%)	9 (45%)
7 – 12 months	9 (45%)	0	6 (30%)
13-18 months	2 (10%)	2 (10%)	2 (10%)
19-24 months	1 (5%)	1 (5%)	2 (10%)
25-and more-	3 (15%)	0	1(5%)

Seventy percent (14) of the parents detected the deafness within the first year (early detection group). The remaining thirty percent (6) of the parents detected their child's hearing problem between the ages of one and three years (late detection group).

In the early detection group, twenty five percent (5) of these parents detected their child's hearing problem by the age of 6 months. These parents reported that they or their parent noticed that the child did not orientate to sound (5/5), and did not verbalise in

the way they had experienced with other babies (3/5). In one instance, a parent noticed that her child startled to heavy vibrations from the wooden floors in their home. She suspected that the child had a hearing problem because experience with a deaf colleague had taught her that that deaf people have heightened sensitivity to vibrations.

The remaining forty five percent (9) of the early detection group detected the deafness between the ages of 7 and 12 months. One alert grandmother in this group suggested assessment when it became clear that the baby had difficulty balancing when sitting and when he started walking. One of this group included a child who had become deaf after contracting meningitis at age 1 year. This child's deafness was picked up within one month. In 9 of the 14 cases parents' and/or grandparents' experience with other children assisted them to detect deafness early.

During the 0-12 month (early detection) period only two nurses identified deafness in the child, one at the 9-month screen and the other at 10 months. The latter mother had mentioned the problem earlier, but her observations were thought by the medical officer to be due to the child's muscular dystrophy and not followed through. Family members detected all other children.

## **5.2 Help-seeking**

Most parents, having detected the problem, whether in the first year or later, sought assistance within the first month (13) or no later than 6 months (4) after noticing the hearing loss. A small group (3) took more than a year to act on this information.

In the early detection group (14), 10 parents sought help within a month, and 4 parents took up to 6 months to seek assistance. One mother noticed a potential problem early, but did not follow through for some time as her family said that the child could not be deaf, and that she was imagining things. In 3 cases the child's maternal grandmother/grandfathers' alerted mothers to potential hearing problems before the child's 9-month check up, but these mothers did not report this at the clinic check up as they felt it might resolve with time.

In the late detection group (6), 3 parents sought help within 1 month, and 3 parents took more than a year to seek assistance. In the latter group, two parents reported that they had been told that their premature babies might develop slower than other babies of a similar age and thought that their babies' hearing might also develop slower. The remaining parent felt the problem would resolve with time.

Some noteworthy characteristics of the 9 parents who failed to notice the problem early and/or delayed seeking assistance for more than a year once they had noticed, are:

- All 6 clinically depressed mothers are in this group,
- 7 of the 9 parents were single unemployed mothers raising their child with minimal support, 4 of whom were also clinically depressed, and
- 2 of the 9 parents were married mothers with employed husbands, but experiencing severe marital discord (their husbands were having affairs). These mothers were the remaining 2 of the 6 depressed mothers.

### **5.3 Diagnosis**

Table five indicates that following detection, almost half (45%) of the group had a provisional or firm diagnosis within 6 months of presenting at a health facility, with a further thirty percent having a diagnosis within a year. The remaining 25% of children were diagnosed as deaf one to two years after parents or clinic screening detected a possible problem.

With regard to the 8 children with confirmed or suspected additional disabling conditions, 2 were detected by 6 months of age, followed up within 6 months and had a diagnosis within an additional 6 months. Two children were detected by ages 7-12 months, followed up within a month and a year respectively and had a diagnosis within a month of help-seeking. The remaining 4 children were detected by parents between ages 2-3 years, help was sought within a month, with a diagnosis within 6 months for 2 of the children and within 1-2 years for the other 2 children.



Parents mentioned the following reasons for delays in diagnosis:

- Recurrent ear infections made diagnosis difficult,<sup>26</sup>
- clinic staff did not always adequately follow up on parental concerns re their child's hearing,
- clinic staff testing refuted parental observations so that parents needed several appointments at clinic/community health centre level before being referred to Red Cross Children's Hospital for further testing,
- faulty equipment at the hospital made reliable diagnosis difficult, and increased time to diagnosis as parents were asked to return at a later time, and
- time between appointments were lengthy, up to three months, because of service constraints.

*Mother 4: detected at 9 months, diagnosed age 2 years 3 months:*

At the day hospital they did the test with the bells and I noticed that she saw them behind her and she would turn around to them so then they said that there was nothing wrong with her hearing, but I insisted that she could not hear.

*Mother 5, detected age 1 year, diagnosed age 4 years.*

When he started walking his balance was very off, my mom told me it might be his hearing. At the clinic they told me there was nothing wrong so I took him to the day hospital...quite often, but they didn't do the hearing test, the proper check-up. Every time I took him to the day hospital they would tell me it was wax build up or he's stubborn or he likes to ignore people.

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<sup>26</sup> High levels of referral of severe chronic otitis media to secondary hospitals indicate the need for improvement of home and/or PHC management of this condition. The provincial paediatric case management guideline for the management of upper respiratory infections (including ear infections) clearly spells out the referral pathway from primary clinics, for the management of chronic ear infections, but it appears that adherence to the guideline may not be consistent. The need for further capacity development for improved implementation of the guideline, and for parent education and support to implement home management (e.g. correct wicking) of ear infections are areas for further attention (Personal communication Ms Leana Olivier, 9/02/2004, provincial coordinator for MCWH, Department of Health).

*Mother 9, detected in first 6 months, confirmed at 9 month after hearing screening was done at the mother's request*

My father used to blow a horn and my brother used to rev his car and this child didn't even look up. Because a normal child would have looked up because they would be scared of a car and a loud shout. So I told the doctor. He said that I was imagining things because of the child's muscular dystrophy....After 2 months they told me she was deaf...So I told them I knew it for a long time, its just that they didn't believe me (Were you quite upset with them?) Yes you won't believe how much. I almost turned (the hospital) upside down with that doctor and all.

*Mother 12, detected at 4 months, diagnosed 1 year and 6 months*

They tested him and they said that he can hear. They made him sit on my lap and then they put this thing here by his ear and they told me that he can hear....They told me to come back in case there was something wrong, then they told me that there was no hearing.....It made me quite upset, actually it made me very upset...Now they tell you it's fine in the right ear, that he can't hear properly, there is still some hearing in the left. The next time they tell you there's nothing or he can hear properly again.

#### **5.4 Conclusion**

Parents and grandparents who had prior childrearing experience seemed better able to detect unusual developments in the child, which assisted in the early detection of deafness. Knowledge of signs and symptoms of deafness might also alert parents to a potential problem. Additional chronic illnesses or acute health problems in the child may make it difficult for health workers or parents to detect a hearing problem. Possible barriers to early detection or diagnosis at clinic and hospital level may include lack of routine screening at clinic visits, poor staff capacity for detection, the use of unreliable methods of detection or inadequate equipment, and the long periods between appointments in a stretched public health service.

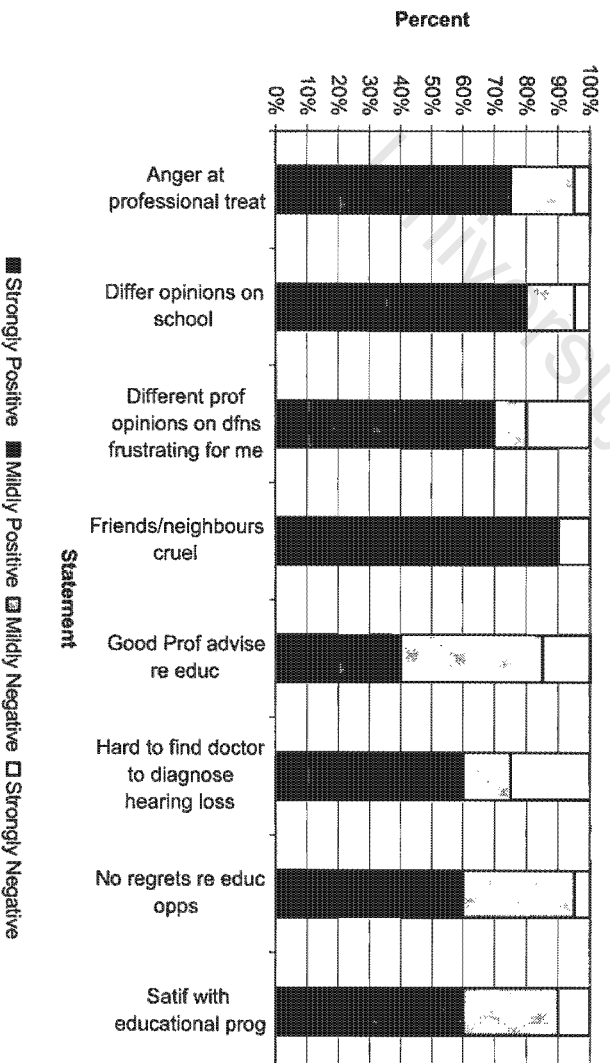
## Communicating with Parents

### 6.1 Quality of professional support

Parents' ability to weather the initial shock of the diagnosis, and to process information related to the impact of deafness on their child, is both a function of parental factors, and of the professional's ability to create a containing environment for the parent when breaking the news.

Figure Three, summarising the relationship items on the Questionnaire, provides some perspective on parents' feelings about the quality of professional input to them about their child's deafness, and neighbours support of their deaf child.

**Figure Three: Responses to the relationship scale**



Related to the scale domain on parental relationship with professionals, table six has the following findings:

- 40% of parents reported that they had received good advice regarding their child's education, while 60% felt they had not,<sup>27</sup>
- 30% reported feeling frustrated by different professional opinions on deafness, while 70% reported that this was not a problem for them,
- 40% reported difficulty finding a doctor to diagnose their child's hearing problem, while 60% reported that they did not have this problem, and
- 25% of parents reported feeling angry at professional treatment of them, while 75% were not angered by professional treatment.

And in terms of treatment of the child by others in the environment.

- 90% of parents reported that they had no difficulty with neighbours' behaviour toward their child, while 10% (2) reported cruelty in neighbours.

Table six further summarises these findings:

**Table Six: Summary of responses to the relationship scale**

SCALE	DEGREE OF DIFFICULTY EXPERIENCED BY PARENTS		
	HIGH 24-32	MEDIUM 16-23	LOW 8-15
PARENTS RATING ON THE RELATIONSHIP SUBSCALE	2	12	6
PARENTS RATING ON THE OVERALL SCALE	0	13	7

In summary, in Table Six,

- 2 (10%) of the parents reported high degree of difficulty in accessing and using suitable professional and other supportive resources,

<sup>27</sup> Most parents rated themselves in terms of access to preschool services and limited exposure to support at the parent guidance and sign language class at the Deaf Child clinic, and an oral parent guidance programme to which some families were referred. The parents of the 5 year old and a 5 year 8 month old also included comments on finding a suitable primary school for their child. This section focuses on quality of professional service. The school items related to the child's school progress (Item no 3, 6 and 18) and professional advice on education (Item 9) are dealt with in Chapter 9 (rearing the child).

- 12 (60%) of the parents reported medium difficulties, and
- 6 (30%) had little or no difficulty accessing suitable professional and other supportive resources for their child.

Parents' experience of professional input when receiving news about their child's disability was influenced by:

- the availability of suitable professional support,
- the nature and clarity of communication by professionals, and
- parental ability to process and experience professional communication as supportive.

## 6.2 Communication barriers

Parents reported experiencing the following communication barriers when professionals conveyed information to them about their child's diagnosis:

### 6.2.1 *Difficulty understanding technical terms or unclear and euphemistic terms used in explanations to parents*

#### *Father 6*

Not labelling often gives people a measure of comfort, but at the same time you haven't (been) told the truth. And (*with the truth*) I think one actually can prepare yourself for what lies ahead, what it's all about.

#### *Mother 6:*

We've been told that he's got a severe hearing multi frequency, and quite frankly it doesn't really say anything.....you can feel, as if they have to protect people and so they try and use as much jargon to sort of colour this thing in almost beautiful. So that you know there is a loss and you know your child needs their help, and he suffers the impact, and you don't fully realise just what it is. Like

with my mom, every now and then she would say he is speaking so well, why must he go to a special school, wear these hearing aids. So the other day I sat her down and I told her, "You know mom, you've got a deaf grandchild and she said: "But you said he is hearing impaired"....I said "(Child's name) is deaf" and, I mean, she was shocked....They are only realising now. I suppose its much easier telling people your child is hearing impaired.

**6.2.2 *Difficulty processing information (parents) or knowing what the parent needs to know (practitioners).***

*Father 5*

To be honest with you, I actually wasn't worried about it (*that the child might be deaf*) because I thought that he was a little bit slow. (Slow to develop?) Yes.

**6.2.3 *Lack of practical education for parents re the implications of the hearing problem, and management of their deaf child***

*Mother 11*

I am the one who has got fears that when we are planning to have another child that can lead for the child to have again a hearing problem (You have not had counseling about that?) No I never did.

**6.2.4 *Faulty parental understanding of their child's condition because of limited knowledge or understanding of what has been communicated to them.***

*Mother 3*

I'm just trying hard to improve everything, because in a way I think that she can (hear) because I got faith in my God that maybe one day she can hear like everybody else. (Do you feel her hearing will improve with time?) Yes, I think so.

*Mother 11*

(Did they say anything to you about speech therapy or learning signs?) They never said anything. The only thing that they mentioned, they gave me some medication

and what they said to me, why they are giving me this medication, it is going to help her hear or talk.

**6.2.5 *Difficulty understanding each other when the health worker and parents do not have a common language in which to communicate, or an interpreter is not used during these consultations.***

Language barriers may make it difficult for practitioners to confirm or communicate their findings to a parent. IsiXhosa-speaking, and some Afrikaans-speaking parents, had difficulty following the input from English-speaking health workers. Where no interpreter was available, parents were given only the bare minimum information about their provisional diagnosis.

*Mother 10 (IsiXhosa-speaking)*

(So in January you noticed that when you call (Child's name) she is not looking...and you're thinking now, she's not speaking properly, so maybe it's her ears?) Yes. (What do you think is the problem with her hearing?) I don't know. (What did Red Cross tell you?) At Red Cross they told me to come here to put on that moulds.

*Mother & Grandmother 11 (IsiXhosa-speaking), through interpreter:* A provisional diagnosis of moderate to severe hearing loss had already been made in the child's file, and further assessments were being done to fit the child for hearing aids. No interpreter had been used during the appointments thus far.

*Grandmother:* When I came to Red Cross they said its only one ear that's got a problem, otherwise they never said anything why (Child's name) can't talk. The only thing they told me is the one ear has got wax. (So you are still not sure what is the problem with (Child)?) No. *(Interviewer to Mother:* And what do you think the problem is?) I don't have an answer because I really don't know why my child is not talking...What they've done, they have checked her ears and they put hearing aids in to know exactly what is wrong with the child's ears. (And did they tell you what they found?) No.

Language barriers can increase or prolong parental concerns, as they see no clear way to express their concerns at appointments. Mother and Grandmother 7, both IsiXhosa-speaking women, with no English or Afrikaans, for example, became very tearful during their interviews. They were unsure what actual problem was, whether it was his hearing, intellectual disability or both, or perhaps some other problem. The interviews proved difficult for these women as they were unable to express themselves directly and the interviewer was not always able to follow their line of enquiry, even with support from the interpreter. The process, mediated by an interpreter, required a lot of time to understand their concerns, and for them to express their emotional distress and settle before being able to proceed. This lengthy process not usually possible in an average assessment, or follow-up service. At a busy clinic available time is primarily used for testing, fitting, follow up and referral of the child's physical problem.

Three of the 5 IsiXhosa speaking mothers also reported stopping regular attendance at the Sign Language and parenting skills class, as an interpreter who had assisted the profoundly deaf, English-speaking sign language teacher and English-speaking parenting skills teacher no longer attended the group.

#### **6.2.6 Lack of emotional readiness for the diagnosis of deafness.**

##### *Mother 4*

You know, everything must still sink into a person before you can really think about his future, especially where his hearing is concerned.

#### **6.3 Communication as support**

Several parents' noted that their attention was primarily focused on managing current challenges. They dealt with their child's needs as they arose, rather than focusing on future needs. Practitioners have to be fairly attuned to the parents' current state of receptiveness to avoid giving too much or too little information about the child's condition at any one time. A clear diagnosis, with the implications for their child clearly spelt out, can be difficult for parents to hear, process and accept, but at the same time can offer



some measure of relief for parents who have been filled with uncertainty about what is happening with their child. Clear, well-timed information can set a point of reference for parents from which they can start to address issues relevant to assisting their child.

*Father 6:*

I knew there was a problem but I never actually realised it was profound...just a little while ago I did a test here at Groote Schuur and then I overheard some of the therapists talking to one another and then I heard that his hearing (loss) was quite profound...When you actually sit down with this report and you see here, shoo, the profound deafness, "working above what is expected". Then you realise just what kind of pressure is on your little child, and he's under five.

During clinical testing, parents would benefit from clear explanations of the purpose and findings of proceedings.

*Mother 12 (re her experience at the clinic/hospital)*

When we found he's deaf, we didn't know what to do. We didn't have anywhere to go. I was actually kind of stuck...If he wanted something he would scream and throw himself on the floor...he only started walking at a year and seven months...They didn't tell us anything...that it can be the hearing that's making him unbalanced...his hearing was tested and I mean, they send you back and I never heard anything (And once you connected with the clinic here?) Then it was actually excellent. The day we came here (Speech Therapist) explained to us, listen here, profoundly deaf means this and explained everything that was wrong with him.

#### **6.4 Conclusion**

Each new development with their child poses a challenge for all parents in terms of accommodating to or helping the child cope in that situation. Clear communication directed at facilitating parents coming to terms with the implications of their child's deafness, as well as information about current choices and future options available to them, can assist the parent to cope with the challenges of raising their deaf child.

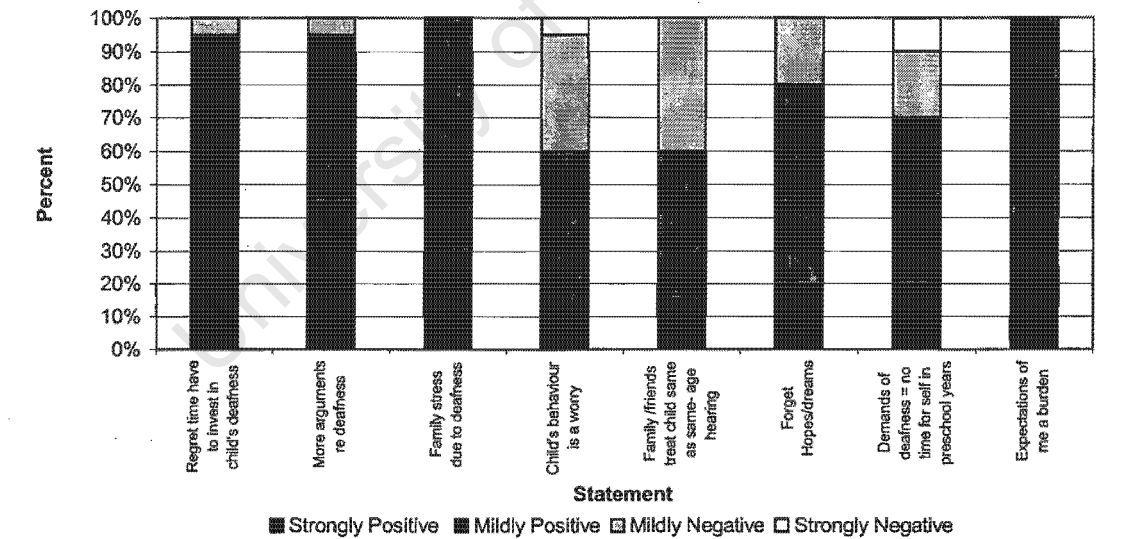
Seven

Sources of Stress for Parents

7.1 Parental views on the impact of deafness on their stress levels

The birth of a child brings about alteration in the “pre-baby” life-styles of parents. It impacts on the parents’ sense of self, personal style, relationships, home and social lives. Figure Four below summarises parents responses to the stress scale of the questionnaire, indicating how the birth of a deaf child impacts on some of these life areas.

Figure Four: Responses to the stress scale



In terms of the scale domain of the effect of the child's deafness on the core and extended family:

- 100% of parents disagreed that family stress was due to deafness,

- 95% of parents disagreed that deafness caused more arguments in the family than usual,
- 100% of parents reported that they did not find expectations of them to care for their deaf child's needs a burden,
- 95% of parents reported having no regrets regarding the time they have to invest in their child's deafness,
- 70% of parents did not feel that the demands of their child's deafness left no time for themselves during the first few years of the child's life, and
- 60% of parents reported that family members treated their child the same as hearing children of the same age.

And in terms of the scale domain on parental satisfaction with the child's progress:

- 80% of parents did not feel that they needed to give up their hopes and dreams for their children because of their child's deafness. 20% agreed that they felt some adjustments to their hopes for their child was necessary, and
- 60% of parents reported that they did not think their child's behaviour was worrisome. 40% reported that they felt their child's behaviour was somewhat worrisome.

In summary, from parent responses to this scale, parents generally reported that they did not perceive family stress or conflict to be related to their child's deafness and that the expectations of caring for their child was not burdensome (95-100%). Most parents (80%) felt confident about the future of their child, while slightly more than half were satisfied with their child's current behaviour.

In Table Seven below, the Stress Scale results are further summarised. Parents' subjective rating of the stress they experience as a result of coping with a deaf child ranged from medium to low stress. None of the parents reporting high levels of stress related to coping with their child.

**Table Seven: Summary of responses to the stress scale**

STRESS RATING	DEGREE OF STRESS EXPERIENCED BY PARENTS		
	HIGH Score 24-32	MEDIUM Score 16-23	LOW Score 8-15
NO. OF PARENTS ON STRESS SUBSCALE	0	10	10
NO. OF PARENTS ON OVERALL SCALE	0	13	7

Themes related to parental coping and stress which were extracted from the more detailed interview data are reported below, and should be viewed against the background of the above "snapshot" stress rating provided by the questionnaire, to contextualise the trends listed.

#### **7.1.1 The Impact of additional disabilities on parental stress levels**

Table 7 (c) in the Appendix provides descriptive statistics from the questionnaire comparing stress/difficulty levels of parents whose children are deaf (deaf subgroup (D), n=14) with that of parents whose children have one or more additional disabilities (additional disability subgroup (AD), n=6). The following was noted:

- Overall trends for both subgroups were similar for high scores (negligible or non existent). A greater proportion of the deaf subgroup scored in the medium range (D = 71.43%, AD= 50%). Parents in the additionally disabled subgroup scoring equally in the medium and low range (50%).
- In the stress subscale, both subgroups scored equally in the medium and low ranges (D = 50% AD= 50%).
- In the communication subscale, most parents reported medium difficulty, with both subgroups similarly represented in this range ((D = 78.57 AD = 83.33)
- In the relationship subscale, the subgroups showed similar trends: Both were negligibly represented in the high range (D=7.14, AD = 16.67). Combining these

scores with the medium range scores, accounted for approximately two thirds of the scores of both groups (D =71.43 AD = 66.67).

In summary, the trends from the *questionnaire* results do not indicate vast differences in the stress and difficulty levels for the two subgroups in this study. However, as previously reported, the *interview -based* results show that of the 6 parents who had children with additional disabling conditions, 3 were among the group of 8 people who were clinically depressed or feeling stressed. The 2 parents whose children were awaiting confirmation of an additional disability were also represented in the clinically depressed/stressed group. This supports literature which suggests that additional disabilities could increase stress for parents of deaf children. As with their child's deafness, parents did not always seem to have accepted or understood the diagnosis of intellectual or physical disability. Five of the 8 parents whose children had confirmed or suspected additional disabilities, for example, reported that they did not feel that their child was additionally disabled, and that any present "slowness" would improve with time.

*Mother 8 (child has chromosomal disorder, with physical and intellectual disability)*

(So the longer the time goes, the bigger the gap in her catching up? Are you very worried about that?) I'm not too worried about that, because I don't think its that serious because she is not mentally retarded, but as far as developing and growing physically, she is not like other children her age).

## **7.2 Stress related to parental approach**

Parents' overt approach to dealing with deafness in their child varied. Some parents seemed actively involved in thinking through, sourcing and using available support to map out ways to reduce the impact of deafness on their child's life. In interviews, where new issues came up that they had not yet thought of, these parents seemed to show interest in finding out more, or wanted the opportunity to access information at a later stage. These active, enquiring, assertive parents tended to have considered options to answer their questions or had the expectation that answers could be sourced with the help of the health worker. They reported expressing anger when this assistance was not

forthcoming and took action to secure answers themselves, such as taking their child to a clinic several times, demanding referral letters, taking their child to a private doctor for an early diagnosis, then returning to public service for follow-up. These "assertive" parents reported stress at *having to ask* for answers to questions and for access to services.

In contrast, other parents seemed to be accepting assistance as it arose, but without personal volition. They tended not to ask questions to help them understand what the intervention might do to assist them and their child. These "accepting" parents hoped for answers and attended sessions in this hope, but made little overt demands on the service or attempts to inform the service about their concerns. During the interviews they had many unanswered questions. These "accepting" parents reported being distressed by *not being told* things they needed to know.

### **7.3 Parents concerns and hopes**

Irrespective of the parents' apparent demeanour (Assertive or Accepting), the interviews revealed the following 3 common trends:

1. Parents were predominantly positively invested in their child's well-being. They had a strong need to know what was happening to their child and what could be done to help them progress well through life.
2. They experienced stress because their positive internal representations of their child's potential for an uneventful and positive future (the assumed child) had been shaken up so that they no longer "knew" how this new, not-usual child would progress through life (the real child).
3. Their concerns re the child's progress through life were underpinned by their worry about the impact of the child's deafness on the child's potential for equal, ready access to opportunities enjoyed by hearing people.

### 7.3.1 Parent's positive investment in their child.

This positivity in both Assertive and Accepting parents is reflected in Table Eight. This table focuses on selected statements from the Stress and Communication scales of the questionnaire.

**Table Eight: Parental view of the child**

No	QUESTION	Strongly Positive Attitude (Score 1)		Mildly Positive Attitude (Score 2)		Mildly Negative Attitude (Score 3)		Strongly Negative Attitude (Score 4)	
1	Regret time have to invest in child's deafness	11	55%	8	40%	1	5%	0	0%
2	Proud of response to Deafness	10	50%	10	50%	0	0%	0	0%
10	Child's behaviour is a worry	3	15%	9	45%	7	35%	1	5%
20	Child handles most situations on par with hearing child	4	20%	8	40%	8	40%	0	0%
16	Forget Hopes/dreams	4	20%	12	60%	4	20%	0	0%

The strongly positive attitudinal direction seen in Questions 1 and 2 (parental investment of self in child) is somewhat diminished in Statements 10 and 20 (parents view of their child's current ability to cope) and Questions 16 (parental expectations of a positive outcome for their child in the future). Most parents were mildly positive, rather than strongly positive on Question 16 (future expectations) and mildly positive or mildly negative (current experience with their child) on Questions 10 and 20.

### 7.3.2 Reworking the assumed child

The above responses seemed to indicate not a rejection of the deaf child or loss of the "well" child, as some theorists suggest. Rather it seemed to reflect concern about the loss or restriction of social opportunities for their child. It reflected a dampening of the inner joy which parents unconsciously feel as they look forward to the unfolding of the development of their (assumed or dreamed about) child. Parental were putting energy into meeting the needs of the child without being sure of the outcomes, or whether they

would be able to obtain support which would minimise the impact of deafness on their child's life.

*Mother 3 (showing signs of distress)*

(Are you ok to talk about this?) Yes I'm fine, I have to be. (We were talking about you pretty much doing things on your own, and its stressful for you?) Sometimes it is, because I don't get help from anybody, when I come to hospital, I just have to come.

*Mother and Grandmother 7, via interpreter*

(Now your daughter is looking a bit...worried about something? Is she worried?) Yes, she worries because it is her firstborn ...*Daughter starts to cry.* (This is very difficult for you. I can see you are worried and sad). Grandmother: No, don't worry. She is only very worried. (Are you also very worried?) I worry, as I like this child. (Can you tell me what is worrying you so much?) The crèche, now the teacher say the boys can't understand him. I want him to go to another crèche and play with other children....*grandmother starts crying and is unable to continue.*

*Mother 16*

I don't have time to think about my emotional side...I did feel a bit of pressure, especially everyone that comes there by us wants to talk about her, and I must report back. And at a point I really felt under pressure because everyone is looking at me, and I'm the one who has to do the driving, to make sure she is here every week.

**7.3.3 Impact of the child's deafness on the child's quality of life.**

Some parents experienced stress because of their strong need to know what was happening to their child and concern about what could be done to help them progress well through life.



#### *Father 5*

(What sort of thing is of concern to you?) Coping and things like that. But I doubt that he is going to hear, I just hope he will... It's always good to be positive about everything. (So you are hoping for the best, but you are concerned that he is going to struggle?) Correct, yes.

This concern was evidenced in parental concerns pertaining to the following key issues which would improve or inhibit the child's access:

- The child's ability to "fit in" with mainstream society,
- access to social opportunities and roles,
- communication difficulties,
- child rearing difficulties,
- limited access to supports for child care,
- limited access to crèche and schooling for their child, and
- financial constraints

These points are further elaborated below and in chapter 8 (communicating with the child) and chapter 9 (rearing the deaf child).

#### **7.4 Lifestyle impact of the deaf child in the family**

The following areas of potential stress were experienced by some parents on a personal level, in the marriage and in the family.

##### **7.4.1 Personal impact**

*Interviews* seem to indicate that parents, particularly mothers, needed to invest a great of time and energy into caring for their deaf child. Some mothers noted that due to the high care needs of their deaf child they were afraid that their families, partners, husbands or other potential child carers would not be able to take care of their child's needs. This seemed to be a combination of the mother's concerns about others'

suitability to provide for the child's additional needs for care and the fact that there were real limitations on alternative available care-giving opportunities for their child.

**Table Nine: Parental perceptions of burden of care**

QN	QUESTION	Strongly Positive Attitude (Strongly disagree)		Mildly Positive Attitude (Disagree)		Mildly Negative Attitude (Agree)		Strongly Negative Attitude (Strongly Agree)	
19	Demands of deafness = no time for self in preschool years	4	20%	10	50%	4	20%	2	10%
22	Expectations of me a burden	3	15%	17	85%	0	0%	0	0%

Parents, particularly mother's, may find that their lives revolve around their children with little or no time for personal attention to self. Nevertheless, parents' responses to statements 19 and 22 of the *questionnaire*, listed in Table Nine above, clearly indicate that generally, despite the *objective* increase in care the children require, these parents do not *subjectively* view their deaf children's needs as burdensome.

#### *Mother 3*

Ever since she's born I've been more religious. I've changed a lot, like I used to go out a lot jolling<sup>28</sup> and even if people would ask me to got out I would say no because of her, she's my life...I don't want to be a burden for somebody else. No, because she's deaf, I can't leave her, because I'm her mother, and I have to look after her. I can't say, listen here, look after her because I want to go out. If I go out, she would go with me.

#### *Mother 16*

I'm not just her teacher, I'm everyone's teacher...When I go home everyone wants to know what did she say, what did she do. And I mean she doesn't do anything and she doesn't say anything, she doesn't seem interested in the therapy at all. And that makes me feel under pressure, but from my husband's

<sup>28</sup> partying

family's side, they are very understanding when I speak about what happened here, and they support me a lot.

#### **7.4.2 Economic impact**

Despite the fact that parents mainly came from poor, working class backgrounds, seven mothers stopped working to take care of their children because of the frequency of hospital appointments and reluctance of employers to give frequent time off. Job losses add to the burden of care. For example, many parents struggled to buy necessities for their child and to afford travelling costs for appointments. Fathers were reported to be unable to attend appointments because of work, placing responsibility mainly on mothers to be the "carriers" of learning and caring for the child's needs.

##### *Mother 3 (who had given up work to care for her child)*

The money that I get, its not that much because I have to clothe her, feed her and come to hospital every Thursday, and if she's sick I have to got to doctor's. (Does her dad give support money?) No, even if I ask him. (And maintenance?) No, because if I ask for maintenance he will ask to have her for a weekend or holidays and I don't want that because he doesn't understand her situation,... he wont be able to care for her properly...I'm quite scared to send her out with anybody. I'm not sure that they will be able to look after her because even my mom has difficulty looking after her. That's also why I can't leave her with her dad, because he doesn't know.

##### *Mother 4*

I decided that I wanted to look after her myself. I wouldn't know how other people would look after her...it would be too much (How do you mean?) She wants everything. Like now, for instance, she would pull on me because she wants something...There are times that it is stressful, especially when she is crying, then I wouldn't know what to do, and then I would hit her, and all of a sudden then she would show to me what she wants. Then I would feel sorry because she just wanted that all along.

*Mother 5 re medical costs*

I thought of letting my parents adopt her, but he (*father*) said no...Then she could go on medical aid and she would have the best of everything, all paid for...If she got sick tomorrow, she'd be fixed within a week. ...Here you have to wait for the results for months and you only follow the appointment five months later because the appointments are all booked up. This is quite frustrating...You know, everything they have done for us was great, it's just the waiting.

*Mother 11, through interpreter*

My husband, there is nothing that he is thinking except always having high hopes that (Child) will hear and will be able to talk. (Has your husband had any counselling about the hearing problem and what he expects for the future?) No. I would like my husband to come here, the problem is he's the breadwinner and he is working alone. Now the jobs are very scarce. Maybe it can cause problems for him, if he is not at work.

**7.4.3 Social impact**

Parents may experience a shift in their life view and social perspective as a result of having to raise a child who is deaf, including dealing with "othering" (being made to feel different or stigmatised) by the hearing community as a result of language, cultural differences, prejudice and lack of knowledge. Like the deaf child, the parent will also need to come to terms with people's experience of their child as different.

*Mother 3 (About her daughter's noisiness)*

Like this morning in the taxi she wanted to scratch in her bag. Now she made a noise, she can't say, "open the bag", so the people were looking at her, and I said to her. "You must not do that." So she just sat and wondered. (Is that unsettling for you?) No, I'm used to that, but I'm just concerned about other people, that I might be offending them.

*Mother 11 (re community response to her child)*

They don't interfere with (Name), except they are concerned. They ask what is this (indicates hearing aids) and why is she wearing this (People don't know much about hearing aids?) No, they don't.

*Mother 12*

When I walk with him to the shop or whatever, I use signing all the time now. Then people look at you, they look at you funny, the way I used to think of deaf people, you know, what are they doing, what's happening... (What was your view before?)...They are not the same like us, we don't have to communicate with them because they, like, got their own culture, if you want to call it that. But when we found out that he is deaf, it changed everything... There is no difference between us, that is what I'm saying.

#### **7.4.4 Impact on parental relationship**

As already noted in Chapter Four, poor parental relations may adversely affect maternal adjustment to the deaf child. Prior difficulties in this relationship can impact on the couple's adjustment to the birth of a deaf baby, and the degree to which they are able to offer mutual support of each other

*Mother 10 starts crying when asked about her own health and reports that her husband is having affairs, and providing no support to her and her child*

(So how did you get money to come here?) I borrowed...If I go home he will tell me to go (Is your husband going to be angry that you came here?) Yes. (This worries you?) Yes.

*Mother 12*

...(So you'll do anything for him?) I'll put him before me, yes (And his dad?) Yes, his father feels the same way (Did his dad find it difficult when you couldn't communicate with him?) We were all struggling, actually. He was also struggling a lot. (But it didn't result in any friction between the two of you?) No, not actually.

#### 7.4.5 Impact on extended family support

**Table Ten: Family treatment of the child**

QN	QUESTION	Strongly Positive Attitude (Strongly agree)		Mildly Positive Attitude (Agree)		Mildly Negative Attitude (Disagree)		Strongly Negative Attitude (Strongly Disagree)	
13	Fam /friends treat child same as same age hearing	3	15%	9	45%	8	40%	0	0%

60% of parents reported that family members treated their child the same as hearing children of the same age while 40% felt that relatives treated their child differently to hearing children of the same age. In the interviews, slightly more than half (60%) of the parents reported positive support from the extended family (12) with the remaining 8 parents reporting that the child's deafness was a barrier to family support. Parents described a wide range of support, from no real support, to wariness regarding assisting the parents in babysitting or managing the child, to overprotection.

#### *Mother 9: (Re her husband's and mother-in-law's involvement)*

Sometimes he helps, but she is not very fond of him (why is that?) I don't know. She used to be fond of him. (How is your husband taking her difficulties?) Quite well. His mother is a bit distant. (Why is that?) I don't know and I don't ask. If you got a problem with my child then you are supposed to tell me. They don't come, they don't phone, seeing that they know how the child is....And she is big now, and they still haven't come to see her, and I don't care. (It makes your angry?) Yes you won't believe how much....I told him if you want to go to your mommy, you can go. Every year I give him that option.

*Mother 12*

(So you get quite a lot of support and understanding?) Yes, too much. (You mean, like interfering?) Yes, everybody is concerned about her. Like, say she's got a cold, then my mother is hysterical.

## **7.5 Supporting parents**

Service offered for their deaf child may be one of the few opportunities that mothers have to obtain support for their child from other parents in a similar situation, and from knowledgeable staff:

*Mother 13*

Where I work, casuals don't get pay if they are not in work, but I don't care about the money. I will work Saturday, Sundays, everyday, but not on a Thursday, because I want to be here myself.

Parents mentioned the following services which they wanted to provide support in addition to the medical services they received:

### **7.5.1 Counselling and support**

The interview situation, which focused on information gathering within an emotionally supportive framework, was a first experience of this kind of support for many of the parents.

### **7.5.2 Group work**

Regular opportunity to attend the weekly groups and have access to support services for their child was experienced by parents as an oasis within an otherwise stressful situation. Parents reported that attending groups offered the following benefits and opportunities:

- Meeting and sharing with other parents facing the same difficulties reduced parents' feelings of being alone in dealing with their child's deafness,
- learning from other parent's experiences and seeing the success stories of other parents gave parents hope for similar progress with their own child,
- lectures and discussions on hearing loss and the level of assistance which can be expected from the use of hearing aids (cochlear implants were not mentioned by parents),
- language development opportunities and sign language tuition, and
- support in sourcing schooling and other community resources.

## 7.6 Conclusion

Parents were positively invested in their children's well-being, and downplayed any stress they might be experiencing as a result of their concerns or daily struggles. This positive investment in the child can be supported in the professional encounter by offering accurate and timely information to parents, creating opportunities for parents to gain support from other parents and by providing an emotionally containing environment in which parents can explore their concerns and stressors without fear of being seen to reject their child.



## ***Eight***

### **Communicating with the Child**

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*Parents seem to assume that hearing aids "correct" the child's hearing, as corrective spectacles may correct common eye problems, but with the degree of hearing loss of these children, the hearing aid can help influence whatever residual hearing the child has, relating to better detection of sound, and assist the child to better associate these sounds with a series of shapes of a mouth, but in terms of hearing the spoken word, hearing aids will not necessarily normalise the child's ability to hear language as hearing people do. The extent to which hearing is impacted upon is also dependent on the child's audiogram profile, and whether the child is post-lingually or prelingually deaf, for example*

*Personal Communication, A Carelse,  
(Sign Language Interpreter and former teacher at a School for the Deaf)*

Chapter Six (communicating with parents) touches on the problem of parents lack of understanding of their child's lived experience of deafness. Parents may be told that their child is deaf and the degree of deafness, but, as hearing people, have no real appreciation of what this diagnosis means in terms of what their child actually does or does not hear.

*Mother 3 about her 3 year old daughter, with moderate to severe (diagnosis pending) hearing loss*

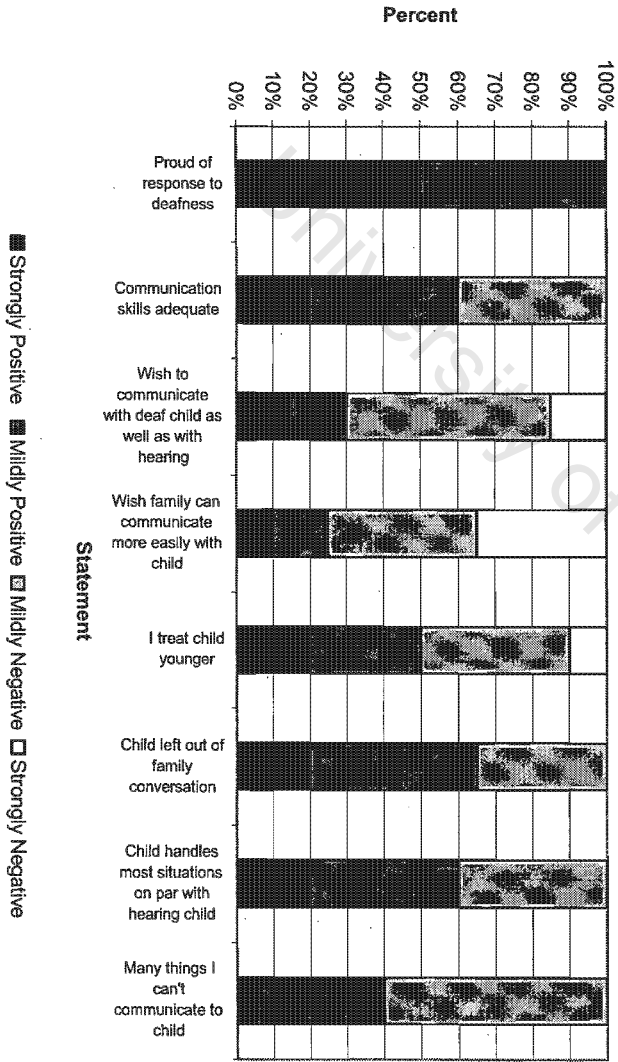
There are some things that I can't understand, like for instance when the phone rings then she would hear it and if the music plays she can hear it. If we call her when she is in another room then she cant hear you...(So there were some puzzling things. That sometimes she seems not to hear, and other times she does. What did you think that was?) I would think that maybe it was the hearing that was coming, maybe her hearing was improving.

Keeping this difficulty in mind, this chapter will outline:

- parents experience of communicating with their child,
- parental difficulties in communicating with their child,
- family difficulties in communicating with their child,
- parents choice of language for the child, and
- parents experience with the use of hearing aids.

8.1 Parents experience of communicating with their child

Figure Five below summarises parents' responses to the Communication scale of the questionnaire.



In terms of the scale domain of the effect of the child's deafness on the core and extended family:

- 100% of parents reported that they are proud of their response to their child's deafness,
- 60% of parents reported that their communication with their children was adequate.
- 60% of parents agreed that there were many things that they could not communicate to their child.
- 70% of parents expressed the wish that they could communicate with their deaf children as well as with hearing children,
- 75% of parents wished that their family could communicate more easily with their child, and
- 65% of parents disagreed that their child is left out of family conversations.

And in terms of the scale domain on parental satisfaction with the child's progress :

- 50% of parents felt that they treated their child younger than hearing children of the same age, while 50% felt that they treated their child on par with hearing children of the same age, and
- 60% of parents felt that their child handles most situations on par with hearing children.

There were inconsistencies in some parental responses to statements 5, 8 and 23:

Of the 60% of parents who reported adequate communication with their children (Statement 5), from their responses to statement 8:

- 25% matched the group who reported that their communication needed no improvement (Consistent response), and
- 35% reported that they wished they could communicate with their children as well as with hearing children (Inconsistent response).

And in statement 23,

- 40% did not feel that their child was left out of family conversations (consistent response) and

- 20% felt that their child was left out of family conversations (inconsistent response).

Of the 40% of parents who reported some difficulty in communicating with their children (Statement 5), from their responses to statement 8,

- 7 (35%) reported that they wished they could communicate with their children as well as with hearing children (consistent response), and
- 5% (1 parent) matched the group who reported that their communication needed no improvement (Inconsistent response).

And in statement 23,

- the same 40% of parents agreed that their children are left out of family conversations (consistent response).

The inconsistencies are discussed in Chapter 10.

### 8.2 Parental difficulty in communicating with the child

**Table Eleven: Summary of responses to the communication scale**

SCALE	DEGREE OF DIFFICULTY IN COMMUNICATING WITH CHILD		
	HIGH 24-32	MEDIUM 16-23	LOW 8-15
PARENTS RATINGS ON COMMUNICATION SUBSCALE	0	17	3
PARENT RATING ON OVERALL SCALE	0	13	7

Table Eleven shows that 17 (85%) of the parents reported medium difficulties with communicating with their child, and 3 (15%) little to no communication difficulties with their child, indicating a slightly greater degree of difficulty in the area of communication, than in the scale as a whole.

Difficulties in communication can put severe strain on the parents' relationship with the child and sense of competency as a parent.

*Mother 9*

It was a lot of strain. We didn't understand each other. If she says "hada hada," no one would understand her then I would have to find out what it is exactly what she wants. She would cry a lot and I wouldn't know why she is crying. I'd have to take out everything just to figure out what it is she wanted. Once I figured it out then I would have to put everything away again and it was very frustrating.

*Mother 11*

It is a problem to me because both of us (*parents*), we don't know the signs and whether she wants something. Because she is not talking, I don't understand. I don't know what she is pointing, and sometimes I'm very busy. I feel that she is delaying me. What she wants, I don't know. Eventually she cries, because both of us don't know what she wants.

### **8.3 Family difficulty in communicating with the child**

The interviews indicated that many parents experienced difficulty in accessing family support because of their child's communication difficulties. This is consistent with findings in Figure Five (statement 11) that 75% of parents wished that family members were better able to communicate with their child.

*Mother 6*

Most of them will always say, you know, they are too scared to talk to him because they're not sure to what extent he can hear them talk. (So why are they scared of him?) I don't know. I suppose most people are scared of deficits. My sister will always ask me "are you going to leave (Child) here also?" and they are very fond of him, but when I am not there, then they get nervous because they are always scared that he's not going to hear when they call him...what if he runs across the road?

*Father 5 (re child struggling to keep up at noisy family gatherings)*

...(So, you feel that other people in the family don't always understand?) Yes, definitely they don't understand. (When he needs to ask to repeat things?) He doesn't, all he actually does is, he sighs a lot. (So it must be extremely difficult for him, if people are impatient?) Yes, that's why even body language is very important. You know, even if you don't say it, he can see. He reads body language better than he reads a book...(So, he takes himself away from noisy situations?) Yes...I will play with him and get him to smile. And I don't like him to stay in those sorts of sulking moods. (So you are checking to see if he is ok?)..It's become a way of life.

Parents may limit their access to family support because of their fears about whether family will be able to adequately communicate with the child.

*Mother 3 (re father's access to his daughter)*

...if I go for maintenance, then he will say he wants her for a weekend or a holiday and I don't want that because he doesn't understand her situation, her condition (Understanding, in which way do you mean?) Because, say, if she wants that pen, the communication between us, I would know that she would want that pen, but he wouldn't know that she would want the pen.

#### **8.4 Parents' choice of language for the child**

The debate on which is the ideal strategy to enhance the communication skills of the deaf child is outlined in the literature review.

**Table Twelve: Parental preference for language choice for the child**

Degree of Deafness	Parental communication preference for child					
	Speech Only	Speech first then Sign if necessary	Sign first, speech later, if possible	Speech or Sign, no special preference	Speech and Sign	Parent did not know
Profound n=6 30%	1	1		1	1	2
Pending <sup>2</sup> n=2 10%		1	1			
Severe n=6 30%	2	3			1	
Moderate n=6 30%	4	1			1	
TOTAL	7	6	1	1	3	2

Table Twelve shows that

- fourteen (70%) of the 20 parents preferred to train their children to speak,
- three parents (15%) were comfortable with their child communicating in speech or sign,
- two parents (10%) parents could not provide an opinion on this issue, and
- parental preferences were not related to degree of deafness or parents expressed level of difficulty in communicating with their child.

#### **8.4.1 Parents who prefer speech to sign language acquisition.**

7 of 14 parents preferred speech training exclusively. The remainder were willing to try sign language if speech training failed. Several factors influenced their preference.

8.4.1.1 *The longing for their children to talk, as demonstrated by this mother, who had not yet received professional counselling on communication options best suited to her child:*

<sup>2</sup> Provisional diagnosis of moderate to severe hearing loss has been made.

*Mother 11*

My husband has got high hopes that (Child) will hear and she will talk, because why is heaven there? If you want to fetch her at the next door and she is still playing with the others she is able to say "hamba", go, go, meaning I am still playing, don't come fetch me now. That is why my husband is having hopes that she will talk (And do you feel the same or different?) Really, there is some way that she will hear. She says "sampa", "give", and then we have hope that she will be able to talk. (And learning to do sign?) Yes I want her to learn the way of sign.

- 8.4.1.2 *Professional advice:* Several parents noted that they had been advised that their children had the potential to learn to speak and that they should focus on speech training exclusively to maximise their child's potential to learn to speak. Parents understood that to use sign language as well would detract from their child learning to speak.

*Mother 6*

I got no problem with sign language. But the teaching at (*oral tradition preschool*) is that there are enough theories claiming that if the child is not going to produce in oral at a very young age, he could miss out on a really important stage. Whereas, my opinion of it is, if at (*oral tradition preschool*) he doesn't cope with the oral he can still go back for sign language, but the other way round, if I didn't give him the opportunity, he'd probably have missed out learning to speak.

*Mother 16, child with severe hearing loss*

(Speech therapist) suggested that if I put her in the (clinic) preschool now then she would begin the sign language with the others and then she is going to be lazy where her speech is concerned and she is going to take it, because if she is doing sign language, she don't need to talk ...she will take the sign as convenience not to talk. Because we want to force her to talk.



- 8.4.1.3      *The equation of "talking" with "hearing"*: Parents assumed that their deaf child's improved speech production was an indicator of improved hearing or normalisation from residual hearing, with parents using the words "talk" and "hear" interchangeably. Parents' observations that their child is able to produce some verbal communication may lead them to believe that interventions (speech training, hearing aids) can improve or restore the child's hearing.

This can be seen in the quotation from Mother 11 above, and below, from *Mother 4, who has a 3 year old daughter with severe hearing loss*

...I think mostly I would want her to talk and not to go where they use too many signs...I would prefer her to talk. I would rather want her to talk at school because then she can feel that she can hear. If we are just going to show her signs then she is not going to take note of our speech. I think a lot about it and I have spoken about it at home, so we just talk a bit louder than we usually did...I don't feel for the sign language (Can you explain why you are not so keen on sign language?) My personal feeling is, just in her case, because I know that she can hear a little bit and we must just talk a lot to her (If people talk to her and she goes to speech therapy and a hearing school, how do you feel that would help her?) It would help her to learn how to talk...I have nothing against sign language, but as I said she can hear and the sign language is going to affect her speech.

- 8.4.1.4      *Social ostracisation*: Stigma attached to being deaf is still rife, and signing is a signifier of being deaf. Parents may want to avoid exposing their child to hurtful experiences by other's treating them as different or peculiar because of their language usage.

*Mother 17 with a son who has severe hearing loss*

I would rather want him to talk. Even if he can learn the sign language, I would rather want him to talk. For me, if he can talk, then I won't worry that he can't hear well. (Can you explain why you want him to talk?) Because I can see that people make fun of him. (You feel that if he talked people won't make fun of

him?) Yes.... But he will talk. He already says mamma. And a child that can't talk won't say mamma. Maybe he is just slow. (Is he slow or is it difficult for him to hear?) The words don't come right...He's normal, he is very clever. (And you aren't sure how much hearing he does have?) No. All they said is his inside ears is not healthy.

- 8.4.1.5 *"Passing for hearing" to fit in:* Parents may want to improve their child's ability to fit in to the dominant culture of the hearing world to optimise their access to available opportunities in this world. They feel that being able to talk will give them greater access.

*Mother 16, child with severe hearing loss*

They said her hearing was not so bad, she can be pressed for speech, because she can hear and sign language is not necessary for her...if I can press her to talk, in time to come when she has to go to school, then she can talk. I will push her to talk for her schooling...the plan is to have her talking so that she can fall in with the rest.

- 8.4.1.6 *Models of deafness:* Available models of adult success for deaf children are mainly based on acculturation to the languages of the hearing world. There are few examples of successful Deaf language usage and success for parents to relate to in forming a vision of future success for their child.

*Mother 16, child with severe hearing loss*

...It's a long procedure. It's not like she is going to talk the end of the year...but it has been shown to me over and over that it can be done...one of the shop owners there by us has a daughter with hearing problems from the age of 2...He said eventually when she did talk she was six years old. So he said everything he did wasn't all for nothing. From there on she went to school and it's her second year on varsity. So, even though she's got a big hearing loss there is something we can look forward to. So we want her to talk, but if that is not possible, we will assist her 100% with sign. (Do you know any adult deaf people?) No.

#### **8.4.2 Parents who prefer both speech and sign language acquisition.**

The following reasons for their preference was noted with these 4 parents:

8.4.2.1 *Additional disabilities:* One parent's (5%) choices were extremely limited. Her child is profoundly deaf and has muscular dystrophy, making speech and sign language acquisition difficult. This mother noted that she would be happy to have either means to improve her child's communication.

8.4.2.2 *Professional advice:* In this instance parents were advised that their children had the potential to learn to speak and would benefit from speech training, but that sign language could be started as well to immediately improve parent child communication.

*Mother 12, child with profound hearing loss. 2 years 5 months*

We had a choice of either the speech or sign language, but the speech will only come later, so we decided to do the sign language as well. (And later) We actually decided because (Speech therapist) told us everything that we can do, so we decided that when he is three we will start with his speech. We already started....Even if he says mommy or signs mommy, we're going to take him out for whatever, it doesn't matter. Yesterday he signed to me "Mommy, you're mommy". And I was quite excited.

8.4.2.3 *Models of deafness:* Exposure to Deaf role models who have made a success of their life roles can provide parents with alternatives examples of language usage and success.

*Mother 12*

I always used to think that it looks stupid...because they were using their hands...but then I saw (Deaf sign language teacher at the clinic) and I saw how everybody understood her except me. And (Speech therapist) told me you can get any kind of work if you can do sign language. There are a lot of people who do signing and they got very good jobs, and they've got good schools.

- 8.4.2.4      *Social ostracisation:* Changes in parents own view of Deafness, and what is "normal", a sense of parental pride in their child's sign language accomplishments, and social ease with their child being deaf in a hearing world might change their view of the acceptability of Sign Language.

*Mother 12*

Because, you know, normally hearing people think, "They are not the same as us". That is what I used to think...But when we found out that he is deaf, it changed everything...There is no difference between us...This one woman in the bus, she asked me what's wrong with him? Why are you using your hands?... (Do you think some people are not aware of sign language?) They don't know there is something like sign language.... Also, even though he is so small he can already sign. They don't know it as sign language, they actually call it speaking in his language. (*With pride*) Yes, he can already do it and you get a lot of comments.

- 8.4.2.5      *Societal accommodation:* Parents may have the belief that hearing culture should adapt to optimise deaf people's access to available opportunities.

*Mother 12*

Say if he is older, and he was sick, I would like him to have a doctor able to understand him when he signs...He must also be independent. I can't always be there for him. He must know that there are also some people that are willing to learn his language...Maybe he's the only deaf child they've ever seen, but there will always be more, not only him.

Mother 12, with regard to schooling

He is going to grow up now with sign language. So all of a sudden just to switch him over to speech, that is not going to work. He'll lag behind and he's not going to be used to speaking and he doesn't like speaking. (Do you want a school where they sign or both?) I would prefer both, but I mean, if it's only sign, that is better for him...My parents view was he can still speak, so we explained to them, ok, fine, at a later stage he will speak, 'cos he is very clever. He already started saying words and things. Maybe he'll speak, but for now he needs sign language to communicate with us. He must have a language, it doesn't matter what it is.

#### **8.4.3 Parents who could not give an opinion**

Both these mothers, interviewed via an interpreter, were IsiXhosa-speaking. As detailed in Chapter Six, they seemed unsure about the nature of their child's problem because of language barriers.

*Mother 10, child with severe hearing loss, age 3 years 6 months*

(Did they tell you here what was happening with her ears?) Yes. (What did they say?) She got a problem with this ear so...*(mother trails off)* (So you not sure what they said?) I'm not sure (And the results of the test at Red Cross?) The result is because she can't hear, she can't understand...She has got a problem with her ears, that's why she is not speaking. (What is wrong with her ears?) She got a problem, she can't understand. (Can she hear?) Yes (So there is no problem with her ears?) *(Mother seems at a loss as to how she should respond)* I am coming to put on the hearing aid.

### **8.5 Parents experience with the use of hearing aids**

#### **8.5.1 Adjusting to the child wearing hearing aids**

Parents may feel some initial shock at seeing their child "suddenly" become deaf, when fitted with aids for the first time. Parents adjust as they see the benefits of the hearing aid for improving their child's communication. In some cases, parents may feel relief as

the child's improved communication is seen as a sign of the child making progress. Parents also have to cope with the child's experience of adjusting to wearing the aids.

*Mother 5*

...I thought they were going to put in one hearing aid. My mom brought him and when I saw him the evening, so he had it on both ears. I felt a bit shocked. But then when I started seeing he was progressing and how improved his speech got, then it was like a normal thing to me. I didn't see it anymore. Just at the beginning when he started wearing it, he was very shy and he didn't even want to go to the mobile shop on the corner, and he didn't want to go to school.

*Father 5*

To me it's not really a problem. When I saw it on him for the first time, I didn't get a shock or anything. To me it was actually a relief because now I know at least the problem is handled and it's going to help him in the long run. To me, that was like the best thing that ever happened to him.

*Father 6*

He said something quite amazing the other day. He said, "Yes, Daddy, it's like riding a bicycle. At the beginning, I couldn't ride my bicycle, and I kept on trying and now I can ride my bicycle. It's the best thing to me, that was actually quite important to see him in that way.

**8.5.2 (Mis)understanding what the hearing aids can do**

The fitting of hearing aids may be accompanied by parental expectations that, irrespective of their child's hearing loss profile, the child's hearing would normalise with the hearing aid, so that the child will be able to hear as a hearing person does.

*Mother 8, child with suspected profound hearing loss and chromosomal disorder*

It's not as bad as it seems. I'm happy, you know, as long as with the hearing aids she will be able to hear normally. It was quite upsetting originally, it was quite upsetting. I knew that she was hearing impaired, it wasn't like a shock. We

had this idea that they could do some operation, then she would be fine. We didn't still think she would have to wear hearing aids for the rest of her life.

Parents may also not be able to make full use of the benefits of the aids for their child, because of lack of knowledge about how the hearing aid works.

#### *Mother 11*

I got two things: Sometimes when I speak soft, she would hear, sometimes I don't know whether the hearing, there is a problem there. I want to ask you, is it operating with a battery? (Yes it does operate with a battery) How long does the battery last? (I don't know. But I will tell them you are having a problem). What I noticed, it normally has a sound, but one time there was no sound, so I brought it back. They never told me even then that you are supposed to have batteries or put batteries after a certain time. But what they did, they put in batteries, but they never told me. (Do you want more information on how the hearing aid works?) Yes (So you have two problems, one, you are not sure how much she is hearing. The other is the hearing aid, how must you manage that?) Yes.

#### **8.5.3 New hope**

The fitting of the hearing aids and education on how to maximise the benefits of these aids gave some parents a new direction in assisting the child.

#### *Mother 4, about her 2 year 3 month old*

I heard in this year that she has the hearing problem. They explained to us and showed us in her folder that it is a nerve in her ear. She's not entirely deaf but there is a problem between 50 and 55. (So that is why she is going to have a hearing aid, to help her?) Yes. But she can hear slightly because say if we say to her "S" then she would say "S"... She is only starting to come right now, and we also know that we must talk loud and clear to her. She must also feel and look to my mouth. (Did you used to do this before?) No I didn't do this before, because I didn't think...(Was it here that they showed you what method would be best to help her with her hearing problem?) Yes...(later) Yes, I'm just glad that I

acted early on the problem, and I think she will improve, with the hearing aid she will improve. She might be able to hear. To differentiate words, and not just sounds, but words.

## **8.6 Conclusion**

Communication is a key ingredient in cementing the growing bonds between the child and its parents, siblings, extended family and community. It is the means through which the family can share the values, beliefs, social rules and life skills needed by their child to integrate into the family and community.

Given that hearing parents have no personal point of reference from which to understand their child's experience of being deaf, improving parent-child communication needs to go beyond the technical teaching of sign language, speech articulation and the use of hearing aids. It needs to work toward maximising parents' understanding, acceptance and development of communication skills best suited to their child's needs.



## Nine

### Rearing the Deaf Child

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#### 9.1 Parental satisfaction with the child's progress

Table Thirteen lists results for selected items from the Stress Scale (Items 10 and 13) and the Communication Scale (Items 14 and 20), to highlight parental satisfaction with the child's progress.

Table Thirteen: Parental satisfaction with child's progress

NO	STATEMENT	Strongly Positive (Score 1)		Mildly Positive (Score2)		Mildly Negative (Score3)		Strongly Negative (Score 4)	
10	Child's behaviour is a worry	3	15%	9	45%	7	35%	1	5%
13	Family or friends treat child same as same age hearing	3	15%	9	45%	8	40%	0	0%
14	I treat child younger	4	20%	6	30%	8	40%	2	10%
20	Child handles most situations on par with hearing child	4	20%	8	40%	8	40%	0	0%
23	There are many things I cant communicate to child	0	0%	8	40%	12	60%	0	0%

Results for these items show that 60% of parents felt satisfied with their child's behaviour and ability to cope on par with other children in the family. 50% of parents and 60% of family and friends were reported to treat the deaf child younger then hearing children of the same age.

## 9.2 Communication and childrearing

The interview data revealed that, generally, problems in child-rearing related to parents' difficulties in communicating with the child. In support of this, Item 23 shows that 60% of parents reported that they had difficulty communicating with their children. The major difficulties with childrearing are reported below with regard to:

- socialising the child,
- disciplining the child,
- establishing a daily routine and
- educating the child.

### 9.2.1 *Socialising the child*

Parents may develop special ways of communicating with their child at home, because of the child's communication difficulties. These become the family norm at home, and the child may have expectations of the same rules applying in other situations. The child may be unfamiliar with the rules of social engagement hearing children automatically imbibe via constant verbal feedback on their behaviour. The communication skill of "turn taking" in conversations, for example, is learnt by participating in conversation, either spoken or signed. The deaf child who has had limited exposure to both languages will not automatically learn this skill. With spoken language, (s)he might struggle to track the fine verbal and nonverbal cues in conversational flow, which can lead to frustration, the experience of social exclusion for the child, distress for the caring parent, and misunderstanding of the child's behaviour in social settings.

*Mother and Father 6, themselves naturally turn-taking:*

*Mother 6* Yes. If he's got a story to tell he wants to say it now. Then we actually have to tell him, no we are not stopping, you wait. You just wait, it'll be your turn now. So now, he does the same to us. When he's just about to finish and I want to tell (his sister) something, then he says, no, no, it's my turn, you wait. *Father 6*: I just want to make a point. If he starts talking, no matter who starts talking after him, no matter who it is, if he starts talking first, then I will listen to him.

*Mother 6* Because he gets angry, very angry. And this turn-taking is very serious...you must not interrupt. *Father 6* Because I know, for him to speak is an effort. And if you ignore him...*Mother 6* then he forgets ...*Father 6* : .When a few people are together he doesn't feel himself part of that group because I don't think he gets the flow of the conversation. So he feels like an outsider, so when he wants to say something, I listen to him. Else, I think, emotionally it will affect him. (*Interviewer to Mother*: You also find he has difficulty at this point with flow?) *Mother 6* : Definitely, especially in my family. Everybody talks at the same time...(So he just sets a limit?) Yes, most of his conversations, we take it for granted, has to be very rigid and artificial. He actually has to learn to do it

Parents may have to contend with social censure when others frown at their children's lack of socially appropriate behaviour.

*Father 6*

(Have there been difficulties that you feel are specifically due to your child's hearing impairment?) I think, definitely the socialising events with people...There are allowances you make at your home for him for the difficulties, and things that you overlook. And you're extremely conscious when you get into a family setting. It's difficult because sometimes what we would allow at home we suddenly have to say no.

*Mother 9*

...I believe that the handicapped must be disciplined (What do you mean by that?) For example, we must teach them a way to eat. Some mother's don't teach the children that. (In the last few months, do you feel it has been easier to do that?) Yes, because before then I didn't know how to do the sign language. Now I can tell her not to do this or that. I would like every mother having a handicapped child to teach their child...I saw a lot of handicapped children and it's a disgrace. I mean, they are only deaf, they are not physically disabled. Maybe you've got a handicapped child, but you don't even know how to discipline the child or you didn't even try to find out...If your handicapped child is disciplined, then he or she can go everywhere with you.

### **9.2.2 *Disciplining the child***

Parents remarked on having to exercise a great deal of patience and tolerance with their child in discipline and limit-setting. Some parents reported that they were not always sure if the child's non-compliance was due to poor understanding of the parent's instructions, testing parental limits or due to "naughtiness". The vast majority of parents reported using hidings for disciplining their children, when the children did not respond to verbal instruction.

#### ***Mother 4***

(How do you communicate with her?) I tap her on her back and say something to her (Is that what you've always done?) Yes, I've always indicated to her. (If she did something you didn't approve of how would you make her understand?) I'll hit her on her hands, for example, I will say, no. Don't do that. (And she responds ok?) Yes.

#### ***Mother 5***

You must speak a couple of times (Is that because he is not paying attention or not actually hearing what you are saying?) Actually both, its complicated. I can't really say one or the other...(Would you say his hearing difficulties have complicated discipline or not significantly?) In a way it did (Can you explain?) I mean, like the days I have to repeat myself many times over and over. (It's frustrating?) Yes.

### **9.2.3 *Establishing a daily routine***

Parents reported that they were coping with developing regular daily routines for their children, such as setting an established sleep-wake routine, eating habits, and teaching other self-help skills. During interviews, parents some times requested information and guidance, particularly in the areas of bedtime routines, potty training and safety concerns.

### 9.2.3.1 Bedtime routines

This centred on the child making bedtime requests, or obtaining reassurance on parent whereabouts when the child is in bed.

*Father and Mother 5*

*Father 5* He just shouts the whole of Liberty, he doesn't care if everyone in the house wakes up: Daddy! *Mother 5* Because he feels you're not responding quick enough and in the meantime, he doesn't hear that you are coming. *Father 5* But his voice, I'm always amused at him, because when he shouts: Daddy!

*Mother 12 (child sleeps in parents room)*

He sleeps with the light on. (For any particular reason?) Not really. I think I can probably switch off the light by now, but we are used to the light being on. (And why do you keep the light on?) They say its best when babies are small. (Does it have any significance to your child signing?) I haven't actually thought about it. But now that I think of it, it's probably best to have the lights on because he would wake me up and then show me "cup". If it was dark he would not be able to do that.

### 9.2.3.2 Potty training

*Mother 5 (deafness diagnosed age 5 years)*

...I mean he was almost three years old and he never used to pee and then I thought he was stubborn...He just didn't want to tell me he wants to pee, he just looked at me. Then my mother would tell me just to put him back on the nappy...(Was your instruction verbal, or verbal and signing?). Verbal and showing. I used to get on the pot myself and demonstrate and tell him what I was doing (And that was because he couldn't hear you?) Now you see, that was where the problem was, I didn't know.

*Mother 4*

...(So she is already on the pot?) I don't know how I got it right. It might be because of the experience with the other three...I just made her used to it. Her father said she would pull him on the nose and show him that she wants to pee.

*Mother 12*

The only difficulty I've got now is potty training. But then I didn't know, but a few months ago I learnt to sign. Then, I couldn't show him and that was very difficult for me. I used to show him that he must go sit on the potty, but he didn't understand. He would go sit and stand up and then he'll have messed on the floor.

#### 9.2.3.3 Safety concerns

*Mother 4*

The road, that is my only problem...I would have to run or somebody that sees will run and grab her out of the road. She doesn't understand the danger...Its been a few weeks that I've been keeping her indoors, but Sunday I was busy with washing, but then I heard the cars were hooting outside in the road...She doesn't understand, she would see the other children playing in the road, but when she's there, she's going to get the strap.

*Mother 3*

I can't leave the door open at home, because she doesn't know that there is a car coming, she would just run. (And when you go places?) I have to keep her hand...It is quite difficult, but it's because I know that she can't hear right. As time goes on I will have to teach her about certain dangers (So you are very patient? ) Yes, I have to be.

*Mother 7*

He plays outside, when the car is coming, he stands in the way...He does not move.

9.3 Educating the child

All the children in the study were of crèche and preschool age. None had ever attended crèche or preschool. This was partly because parents could not afford local crèche fees, however minimal. Parents noted that financial problems aside, language constraints and other health problems prevented them placing their child in a preschool. They felt that available preschool facilities would not be able to cater for their deaf child's needs.

The questionnaire items on education are aimed at assessing parental satisfaction with educational services available to their child. 18 parents had not yet discussed educational opportunities for their child. Only 2 parents had started to think about primary school placement for their children, aged 5 years and 5 year 8 months.

The group of 18 parents' knowledge about "education" was therefore restricted to the service provided at the Deaf Child Clinic or the referral sites recommended by the clinic. They equated educational progress with speech and sign language gains made by their child. The remaining 2 parents had been given brief information on the local schools to which they could apply for placement of their child in Grade R or Grade One.

The responses outlined in Table Fourteen below, should be viewed in the above context.

Table Fourteen: Parental satisfaction with information on education

NO	STATEMENT	Strongly Positive (Score 1)		Mildly Positive (Score2)		Mildly Negative (Score3)		Strongly Negative (Score 4)	
3	Differ opinions on school	7	35%	9	45%	3	15%	1	5%
6	Satisfied with educational progress	6	30%	6	30%	6	30%	2	10%
9	Good professional advise re education	4	20%	4	20%	9	45%	3	15%
18	No regrets re educational opportunities	8	40%	4	20%	7	35%	1	5%

Table Fourteen summarises parent's responses to the educational items on the Relationship scale of the questionnaire, with the following findings:

In terms of the scale domain on parental satisfaction with the child's progress:

- 60% of parents reported satisfaction with their child's educational progress.
- 60% reported that they had no regrets regarding their child's education to date<sup>29</sup>

In terms of the scale domain on parental relationship with professionals:

- 40% of parents reported that they had received good advice regarding their child's education, while 60% felt they had not.
- 20% of parents reported that they were given different opinions of schooling for their child, while 80% reported that they did not experience this problem.

In summary, in the context of this study group, these trends specifically reflect the following findings for this group of parents:

#### **9.3.1 Parental satisfaction with the child's educational progress**

- The 60% of parents who reported satisfaction with their child's educational progress were happy with gains their child made in sign language or speech therapy classes recommended for their child, while
- the dissatisfaction of 40% of parents with their child's current level of progress related to barriers to speech and language gains. This included:
  - barriers to parents and children accessing sign language or speech therapy services in their native tongue,
  - difficulties experienced in making communication gains because of the child's other health problems,
  - parents expecting greater improvement in the child's hearing and speech than was actually experienced with treatment.

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<sup>29</sup> These school related items are listed as part of the whole Relationship Scale in Ch.6, and discussed here.



### **9.3.2 Educational advice for parents**

The 40% (8) who were satisfied with advice on education had not received any advice beyond the weekly parent guidance class and sign language training at the Deaf Child Clinic or the speech training and parent services offered at Carel du Toit Centre at Tygerberg hospital<sup>30</sup>. They felt that this was sufficient for their needs at that stage and reported that they did not feel the need to discuss preschool or primary education options for their child as yet.

The 60% (12) who were not satisfied with advice on education, were very positive about the relief and improved knowledge they experienced once referred to the Deaf Child Clinic. Those referred to Carel du Toit parent guidance programme were pleased with the assistance in speech training and parent support offered there.

However, this group did not feel that they had a good understanding of the scope and range of services available to their child for hearing, speech and language choices. They would have preferred the current parent and language classes offered to be more frequent, and more easily accessible from their homes and to other family members. They would also have liked preschools and other facilities closer to their neighbourhood to have staff who understood their deaf child's needs in the way experienced at the Deaf Child Clinic and Carel du Toit Centre, so that they would feel comfortable to use these services for care and support for their child. 50% (10) of this group also did not have a need to discuss formal schooling for their child at this stage, while 10% (2) felt confused and were not satisfied with the range of information they received on formal schooling.

The 18 (80%) parents who responded to the item that they did not experience a problem with been given different opinions of schooling, had in fact not discussed the issue of formal education with practitioners at all. The remaining 2 (20%) of parents who had

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<sup>30</sup> The researcher observed in discussions with hearing centres and Deaf centres for parent support that there did not appear to be a good working knowledge by one group of centres, of the services offered by the other group, so that parents only hear about the set of services used by their contact organisation. None of the parents in this group had any knowledge of audiology and parent-child support or sign language services offered by local Deaf NPOs, nor did the representatives of the Deaf organisations spoken to always have a good understanding of the services offered in hearing-run public health centres.

discussed education reported that they were given no or restricted information on schooling:

*Mother 5*

(Have you thought about what school you are going to send him to?) Yes, I'm sending him to a normal school. (And what did they say about him managing in the class?) Well, no one spoke to me about putting him in special school or anything, so I just went ahead... (I'm not suggesting you put him in a special class. Just that perhaps it would be better, just to check what sort of stuff he would need from the teacher, and in the classroom? ). *Father 5* I'm listening to what you are saying, it's actually something new. *Mother 5*: I haven't actually thought about it because...*(Interviewer interrupts, feeling uncomfortable about stepping into a practitioner role during the interview: I'm not suggesting, I just think you should discuss it with somebody?)* *Father 5* Now that you've mentioned it, that's what I'm saying. *Mother 5 continues*: It never crossed my mind, come to think of it, because when I spoke to his teacher in preschool and I asked her, but this was actually before he had the hearing aid...*(the parents clearly wanted to follow through on this issue and briefly discussed the issues they wanted information on and who they would consult after the interview to clarify their choice of school for their son).*

The 2<sup>nd</sup> set of parents had been given one option, but chose to visit all the other schools on their own initiative to see first hand what was on offer for their child, before settling on the primary school for deaf children originally recommended by their child's oral preschool programme.

*Mother 6*

(Child) is used to being in a small class and 40 children are in the normal state schools. That would be too much. Also with having to come to terms that his hearing loss is far greater than what it was thought. The (oral preschool) thing is that if you put your child in there then your child must remain there. Of the special schools only one was regarded as the main deaf school, other than the normal school. They keep the same pace and the same rate, and the only

difference is that they have about 5-8 children in the class. The teachers are language teachers, so they've got the extra. (*Parents describe the pros and cons of the schools visited*) *Father 6*: You know, from what I've heard and what I saw, (recommended school) is by far the best.

#### **9.4 Conclusion**

Communication, both verbal and nonverbal, is the currency which flows through parent-child interaction to transmit family culture. It helps establish the everyday ebb and flow of family activity and routine needed to provide the secure framework within which parent and child can relate. Hearing parents of a deaf child need to deal with the same everyday tasks and child-rearing challenges faced by all parents. They could manage these with a greater degree of success if provided with early support to address communication barriers and other difficulties which might interrupt the flow of parenting.

## Discussion of Results

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*"Despite all efforts to be objective, it also is true that the way in which the pieces of the puzzle are assembled here and the conclusions drawn from them are significantly affected by my own theoretical views. Recognising that fact and believing that we are still some way from a complete understanding of deaf children's psychological development, I consider most of the conclusion drawn here to be tentative."*

In Marschark, 1993, *Psychological Development of Deaf Children*, page 5.

Chapters four to nine addresses the broader aim of this study, documenting hearing parents' experiences of the impact of deafness on raising their deaf children. This chapter discusses the findings in terms of some of the barriers and opportunities for successful parenting highlighted by parents' experiences. Specifically, it provides comment on the following study objectives:

- **psychosocial issues** hearing parents may experience in raising their deaf child, including the impact of deafness on marital and family functioning (Section 10.1),
- parental **experience of services** available to them and their child and perceived usefulness of these services for their needs (Sections 10.2) ,
- parental **attitudes toward deafness** and the impact of these attitudes on parental coping with the child's deafness (Section 10.3) and
- parents' perceptions of the **child-rearing issues** they have experienced as a consequence of the child's deafness (Sections 10.4)

The final objective of the study is to make preliminary **recommendations for improving services** to parents, specifically in the health sector. Recommendations will be discussed in chapter eleven.

## **10.1 Psychosocial issues**

Zeanah, et al (1997), in a 10 year review of research on infant developmental risk reports on several risk factors which may increase parental stress and reduce personal and psychological resources available to nurture young children. Factors related to the child include prematurity, serious medical illness and the infant's biological or temperamental response to stress. Factors related to the parents include adolescent parenthood, parental psychopathology (in particular maternal depression), violence toward the child, high levels of marital conflict and low parental intimacy. Poor quality of infant-caregiver attachment, poverty and low social class are also listed as risk factors in this review.

Chapter four outlines the key demographic characteristics of the parents and children included in this study. The data shows that several of the above factors were present in various combinations in this study group, namely serious medical illness, adolescent parenthood, marital conflict, poverty, low social class and maternal depression.

Two of these issues are highlighted here: economic adversity and maternal well-being.

### **10.1.1 *Economic adversity***

Luterman (1979) found that in his parent support service, parents from lower socio-economic backgrounds attended and actively participated less in parent support groups than middle and upper class parents. He felt that that this was a reflection of the former group having multiple stressors which left less energy to devote to the parent programme, despite equal interest in the well-being of their children.

All parents in the study were from low income backgrounds. 50% (10) were formally employed in low income jobs and 50% relied on casual income, or lived on the income of other family members. Seven (35%) mothers stopped working due to the high care needs of their deaf child. Mothers noted the additional burden of care which poverty placed on them in terms of providing for their child's basic needs. They reported lack of funds for preschool care, increased costs of their child's health needs in the form of travelling costs for appointments at the specialised deaf child clinic, costs of batteries for

hearing aids and other related costs. Financial strain was also felt in terms of the loss of earning capacity from having to be off work due to child care. None of the unemployed mothers had information about their eligibility for a childcare grants.<sup>31</sup>

#### **10.1.2      *Mental status of mothers***

A comparison between well mothers and stressed or depressed mothers supports Zeanah et al 's (1997) findings: Maternal depression, marital or familial conflict, and having a child with an additional disabling conditions over and above deafness, appeared to increase the burden of care for these parents. Zeanah et al (1997) suggests that these risk factors may negatively impact on parental ability to negotiate the adjustment to their child's disability.

Beazley and Moore's (1995) contend that interventions should focus on strategies which enable parents to overcome environmental barriers and focus on their strengths. Strategies should include interventions aimed at promoting sound infant- caregiver attachment and coping strategies for adolescent parents. Treatment and support for maternal psychopathology should be provided. Marital counselling, parenting skills, coping skills, and assistance to access available financial supports could improve the parenting experience. (Beresford, 1994, Zeanah, 1997, Richter, 2001).

Kisor (1994, pg 17) reflecting on his own parents reactions to hearing that he was deaf, noted that his parents initially "suffered the classic reaction of emotional devastation", and were hard pressed in the oral, service-deprived, war years of mid-1940s to map a meaningful pathway for their child. It is his opinion that his parents "greatest resource was their robust self-reliance". It is this self-reliance, and personal strength of parents, that should be sought out and supported by those who work with parents of the deaf.

Definitive statements regarding protective factors within this group of parents are not possible due to the small numbers. This would be an interesting area for further study,

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<sup>31</sup> The child support grant is a poverty alleviation grant paid to parents with children 7 years and younger. Care dependency grants are paid to parents of children age 1-18 years with severe physical or mental disability receiving full time care at home. Children with severe physical and mental disability may be easier to identify as eligible for this grant, whereas the lack of early diagnosis and the more subtle impact of deafness on parents and families may not be so readily identifiable.

to identify areas to be strengthened in local parents. For example, the influence of maternal education on child health is well recorded. 18 mothers had Grade 6 to Grade 10 education, 1 had Grade 12 (Matriculation) and 1 was at Technicon, with most mothers having finished Grade 9. On average people living in the Western Cape are reported to enjoy amongst the highest levels of primary, secondary and tertiary education in the country (Census, 1996 and 2001). These mothers relatively high levels of education is not unusual in this province. It would be interesting to assess whether parents who managed to access and sustain attendance at this specialised deaf child clinic were better educated than the average parent attending the service as a whole.

## **10.2 Parents' experience of services**

The next section focuses on the enablers and barriers to early detection, help-seeking and diagnosis of deafness noted in chapter five. It is followed by discussion on the findings in chapter six on how professional interaction can impact on parents' experience of receiving the news about their child's deafness.

### **10.2.1 Detection, help-seeking and diagnosis**

#### **10.2.1.1 Parental factors**

Results indicate that, during the first year, experienced parents had expectations that their babies would begin to respond to instruction or wave or smile on request. These parents also had an expectation that their child would begin to develop language and looked forward to their child's first words. In the study group, when their child either did not verbalise or verbalised differently to what the parent expected of a child of this age, or failed to age-appropriately respond to parental requests, most of these parents were alerted to the possibility of a problem with the child's hearing. The parents' and grandparents' knowledge and experience of what is usual in a child's development assisted them to detect the child's unusual behaviour. For a smaller group of parents, exposure to deaf people on television, in their neighbourhood or at work alerted them to signs that the child might be deaf, such as the child not reacting to sound, but startling to vibrations, or having problems with balance.

Detection seemed to be delayed by lack of parental knowledge about development of communication in the hearing or deaf child. Parents without personal, interpersonal and economic supports were also less equipped to detect and respond to deafness in their young child. For example, the nine parents who failed to notice or to act on their knowledge and seek assistance included all 6 clinically depressed mothers, 7 single, unemployed mothers raising their child with minimal support and 2 married mothers with severe marital discord.

In this group of parents, help-seeking was delayed by 6 – 12 months. This was due to non-detection (not noticing), avoidance (the hope that the child would outgrow it), denial (not reporting their suspicions to health workers), or lack of energy to follow up suspicions because they were depressed, stressed or overburdened.

#### **10.2.1.2      *Health worker factors***

Health workers who are not adequately trained in the importance of early detection to prevent ear disorders or to promote early assistance to the family of the deaf child, may not sufficiently prioritise hearing in the screening of children.

Study results suggest that the poorly trained or busy health worker may either be overly reliant on parent reports of sound hearing, or be dismissive of parent reports of hearing problems. They may shortcut good clinical assessment, and fail to do hearing tests in a reliable fashion. Primary health care screening detected only 2 of 20 children, with the rest detected by families. Two mothers had had rubella during pregnancy, yet it seems that their children were not prioritised as at for developmental delay or deafness. These children's hearing loss was detected by family (4 months and 2 years 6 months) and thereafter diagnosed at the clinic (1 year 7 months and 2 years 6 months respectively).

Following detection and help-seeking by families, 45% of the children had a diagnosis within 6 months of presenting at a health facility. Delays beyond this were due to recurrent ear infections, faulty equipment and lengthy time between appointments, as well as clinic staff not always following up on parental concerns about their child's hearing. Inaccurate testing also refuted parental observations. With regard to this latter



point, caregivers have an intimate knowledge of their child's behaviour, compared to the health worker. Health workers assessments do not always yield reliable results, and they would do well to consider parents as expert partners in assessment of the child's health status at appointments (Deyo & Gelzer, 1991, Marschark, 1993, WHO, 1998).

In summary possible barriers to help-seeking or early detection by parents or health workers include:

- lack of sound knowledge of what to expect from a developing infant. This includes information on the normal range of infant verbalisations and responsiveness in the hearing child, and what can be expected with the deaf child,
- lack of parental or family readiness to deal with their suspicions that the child may be deaf,
- parents failing to report suspected problems on their own initiative at clinic appointments, even when asked as part of developmental screening,
- inadequate screening for deafness at clinic visits, and/or failure to follow through on parental enquiries about a possible hearing problem in their child,
- reduced parental ability to notice cues to their child's hearing problem, as a result of a combination of disabling factors such as severe economic adversity, maternal depression, severe marital strife and having to deal with other disabling health problems in the deaf child or the child's sibling.

## **10.2.2 Communicating news to parents**

### **10.2.2.1 Professional communication: Giving the news**

Effective communication by the health worker requires understanding of the parents' current knowledge about their child's deafness. Providing appropriate information can help to clear up misconceptions about the child's condition, as well as help parents process the meaning of the child's hearing loss, both on a practical and emotional level.

As already noted, Beazley and Moore (1995, p.33) and Gregory (1995) report a significant link between parental ability to cope with a diagnosis of deafness and the

approach, beliefs and practices of service providers who break the news and provide supportive services to the family. Health workers who hold stigmatising views on Deafness, lack a working knowledge on deafness and communicate with parents only from a deficit based perspective may contribute to parental difficulties. These parents may struggle to process the news of their child's deafness and to mobilise energy to optimise their child's developmental opportunities.

Comments from participants suggest that parents may have difficulty understanding and interpreting communications from health workers regarding their child's health, including information about the child's hearing loss. The use of jargon, or non-specific terms may make it difficult for parents to grasp the nature and extent of the child's deafness and its impact on the child's actual potential.

Health workers may shy away from directly naming the fact that the child's is deaf in an attempt to soften the blow for parent's hearing about the child's deafness. The use of euphemisms may delay parents' absorption of the news and adjustment of their expectations of their child.

Health worker's ability to provide accurate information is further complicated when the health worker and parents do not have a common language in which to communicate, or an interpreter is not used during these consultations.

Lack of training in the sharing of difficult information may result in the health worker appearing cold and uncaring when giving the news without necessary containment, with significant impact on the parents.

Health workers may also have limited time during consultations to communicate effectively to parents, and parents may see different health workers at each consultation. When parents have been seen by more than one practitioner, each may assume that someone else has communicated the facts to the parents. Parents may then go from one professional interaction to the next without having a solid understanding of the child's diagnosis, next steps in the process, and options for longer term coping with the challenges ahead of them.

#### **10.2.2.2**

#### ***Parental readiness: Processing the news***

Hearing parents may have anxieties related to discovering that their child is deaf and fears about how they will cope, which can reduce their readiness to be receptive to news that the child is deaf, even where clear information is given by the health worker (Luterman, 1979). The initial shock, and ongoing concerns about the challenges they will need to negotiate, can be emotionally taxing. It can reduce parents' ability begin working on ways to cope with their child's deafness. Further, parents hoping for the best results for their child may read more positivity into a communication than is intended by the practitioner, if communication is not specific and clear and parent's understanding of what has been said is not checked.

### **10.3 Parental attitudes toward caring for their deaf child**

Attitudes and beliefs can positively or negatively impact on the way in which we view events in our lives, influencing the amount of stress we experience in relation to those events.

#### **10.3.1 *Parents' perceptions of their levels of stress***

Parents generally reported that they did not perceive family stress or conflict to be related to their child's deafness and that the expectations of caring for their child was not burdensome (95-100%). Most parents (60-70%) reported that their experience of caring for their child was not excessively stressful. 80% felt confident about the future of their child, while slightly more than half were satisfied with their child's current behavioural adjustment.

The positivity demonstrated by these parents does not support a "doom and gloom" view of hearing parents with deaf children. As described by Hewson (1997), parents' reactions are contextual and dependent on many factors. These include the context within which they are coming to understand the meaning of deafness for their child, their

current experience of coping with caring for their child, and the availability of assistance to reduce their stress.

The positivity reflected in questions 1 and 2 of Figure Four might in part be due to the fact that some parents had not processed the initial shock of this news. These parents may have put aside the emotional strain of their situation to focus on the hands-on, daily issues of raising a deaf child. Keeping a positive and hopeful attitude can act as protective measure to help them cope with their situation. For some parents their energy is directed toward a "survival mode", with little opportunity for processing emotional issues. Many parents in the study had not thought of the emotional impact of their situation until they were asked to reflect on their situation in the interview situation. Where parents are not adequately assisted with their difficulties, and new challenges are added to these, this "survival mode" may become the parent's customary way of coping. For other parents, this positivity may reflect parental flexibility, resilience in accommodating to the needs of their children and the presence of sufficient supports to work on their current issues of concern.

### **10.3.2      *Positive investment in the real child***

Results indicate that parents were strongly invested in their child's well-being. The slightly less positive response to questions reflecting their hopes and dreams for their child's future, seemed partly a factor of parents' concern about the implications of deafness for the child's development and well-being, and partly due to the reality of service constraints for deaf children.

Parents may start with an unspoken dream that their new baby will automatically develop toward greater skill and personal ability. Parents entertain the hope that their Assumed Child will progress positively through the milestones of life, developing family bonds, making friends, being successful at school and work, starting intimate relationships, considering marriage and starting their own family.

The diagnosis of deafness, and its potentially disabling effects, may interrupt or shake up an unspoken, unformulated Life Plot parents may have for this Assumed Child.

Parents in the study group, in different ways, seemed to be trying to establish to what extent this "Life Plot" would need to be reworked. They seemed to be trying to get it back on track, with accommodation to the child's deafness. Parents' in the study group hoped that the interventions of health providers would assist to re-establish the Life Plot with minimum impact for the child. In support of Hewson's (1997) episodic stress reaction model, their focus was primarily on here-and now difficulties in finding these new directions.

While this seems appropriate, in keeping with parents' tendency to deal with their children's developmental needs as they arise, the underlying assumptions on which this is based may at times be different for parents of the deaf child: The parent of a hearing child lives with the comfort of naively assuming good progress for their child. The parent of the deaf child, having had these assumptions newly shaken, may live with the fear of an unsettling, unknown future for the Real Child. Until adequate support becomes available, focusing on the here and now may offer emotional protection, where living in the present, one day at a time, may be a means of coping with an otherwise overwhelming situation. Supporting parents' efforts to find solutions to problems and to engage with the Real Child positively supports the parents both practically and emotionally.

In Table Eight (Parental view of the child), it may be that parents' strong hopes for a positive impact (Statement 16) of their actions (Statements 1 and 2) is tempered by some uncertainty regarding their child's resources to cope with life challenges (Statements 10 and 20). Parents seemed strongly protective of their child, and in some instances, may have downplayed the impact of managing their child's deafness. Perhaps they felt that acknowledgement of their own fears would be perceived by the researcher as an indication of lack of positive feeling toward their child, rather than realistic concern about challenges they faced. This does not necessarily indicate lack of acceptance within the parent, but protection of the child and family from the potentially pathologising gaze of the health worker. This can inadvertently deprive the parent from a supportive, understanding and non-judgemental environment within which to think

through a preferred response to a stressor.<sup>32</sup> On the other hand, in line with the episodic stress response model (Hewson, 1997, pg 1132), it may be appropriate for the parent at that time to downplay stress as a protective measure during a crisis period, until they gain sufficient personal and other resources to manage the current situation.

### **10.3.3 Supporting parents to find solutions to crises**

Assertive, enquiring parents may actively engage with the health worker to re-establish a positive directionality for themselves and their child. Health workers may see them as demanding, rather than in need of professional containment and support. To reduce their own stress at parental "demands", health workers may ignore parents concerns, or conversely, give more attention to assertive parents' concerns than to those of parents who quietly worry. As parents tend to voice their concerns by focusing on practical problems, the thrust of this help may be brief, often poorly digested technical responses. This does not take into account the anxiety such responses may evoke in parents who do not understand the *meaning* or implications of this information for the child's overall well-being. Outward expressions of positivity by parents may also mask real concerns which may then never be addressed as parents put these aside in the interests of focusing on obtaining practical help.

In part then, hearing parental estimations of their own levels of stress, as indicated in Figure Four may be, for example:

- a necessary downplaying due to the parents need to remain positively directed toward their child's needs. This may be appropriate until the parent is enabled to cope with their current situation.
- a necessary downplaying due to the parents' experience of a lack of space in the healthcare interaction for parents to safely engage with any emotional strain they may be experiencing.

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<sup>32</sup> The researcher found that creating a climate of acceptance for parents' less pleasant experiences with caring for their child, seemed to free parents to discuss these, without fear of judgement of themselves as parents or of their children. This would be enabling of parents using such interactions to think through workable, acceptable solutions to their difficulties. The time to create this accepting environment is not always available in a busy clinic, where different health workers may see parents on each occasion.

- An indication of parental investment in creating a positive environment for their child, having found solutions and supports with which they are comfortable.

Irrespective of a parent's presenting demeanour, health workers should be prepared for the likelihood that a diagnosis of deafness creates some degree of stress for hearing parents, both at the time of diagnosis, and as new challenges arise. This reaction should not necessarily be viewed as an indication of a pathological reaction to the child being deaf by the parents. It may instead indicate the need for support to rejuvenate parental energy to improve their child's situation. Parents should be encouraged to voice their concerns at their own pace and from their own perspective in a caring and contained interaction with the health worker. Information should be available to assist parents to make informed decisions for their child.

In terms of Beazley and Moore's (1995) thesis on the need for practitioners to be enablers of parents, rather than disablers, Hewson's (1995) model on the episodic stress response can provide a framework within which practitioners can avoid pathologizing parents' emotional reactions and ongoing concerns. Health workers should focus on empowering parents by partnering with them in deriving solutions to their current crisis, thereby promoting emotional containment, and freeing parental energies for their core business of child-raising.

#### **10.3.4      *Differentiating crises from pathology***

The above discussion is not intended to deny that there may be psychological difficulties or psychiatric pathology which may at times reduces parental resources to cope,<sup>33</sup> and for which intervention will be needed.

Parents identified as having a mental health problem in this study, for example, declined permission for this information to be shared with the clinic team, preferring separate referral for this aspect of their care<sup>34</sup>. Mental health conditions are in themselves stigmatising and potentially disabling, and people may delay seeking mental health care

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<sup>33</sup> See the findings of this study on maternal depression, for example.

for fear of being seen as “mad”, or because of their experience of their usual health care environment as being insufficiently emotionally containing for the sharing of emotional pain.

#### **10.3.5 *What works to provide practical and emotional support?***

In a busy clinic or hospital setting the health worker who breaks the news is often not in a position to offer the necessary amount of time for emotional holding needed by parents. Other options are needed for further support. Those suggested by parents include individual counselling sessions, support groups and educational information.

Counselling focuses on assisting people who are otherwise well functioning in all aspects of living, to think through and develop strategies to cope with and improve functioning in areas where they are experiencing stress. (Ivey and Simek-Downing, 1980).

Luterman (1979) suggests that a counselling service should be offered as part of the overall parent support and educational programme, not as a stand-alone service. In the latter case, support and educational staff tend to block out or to remain unaware of affective issues by referring them to the counsellor instead of developing and adopting a supportive approach in all aspects of their work with parents. Professional counsellors or psychologists, where available, can instead be used for staff training and consultant support on psychosocial and mental health issues, as part of team meetings and processes, and to inform management of complex mental health related issues which are not manageable by the clinical team (Luterman, 1979, Mental Health Programme, Department of Health, 2004 ).

The sections which follow discuss issues which impact on parents' experience of rearing their deaf child. As communication is a central issue affecting all aspects of child-rearing, it is discussed extensively before addressing issues related to the parental tasks

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<sup>34</sup> These mothers were referred for mental health care to appropriate public health or NGO mental health services close to their homes.



of socialising the child, promoting emotional development and making educational choices for the child.

## **10.4 Rearing the child**

### **10.4.1. Communication between parent and child**

#### **10.4.1.1 *Difficulties in communication***

In chapter eight, eighty-five percent (17) of parents reported medium difficulties with communicating with their child and fifteen percent (3) little to no communication difficulties with their child.

Responses to individual questionnaire items showed some inconsistencies in parental responses regarding the adequacy of their communication with their child. These inconsistencies may be due to parental ambivalence. Parents may feel torn between their need to be able to communicate well with their child (a wish fulfilling positive response to items) and the very real day-to-day struggle to improve their own and family members ability to communicate with the child (a reality- based response to items). Parents may not feel able to own any difficulties in this area, as this may be perceived as an indicator of parental inadequacy and helplessness to meet their child's needs. As a protective strategy, some parents may tend to overestimate the adequacy of their communication skills with the child to "ward off" any experience of parental inadequacy. This would help them retain a positive attitude toward their ability to constructively impact on the future of their child.

Parental ambivalence may also be due to the many uncertainties which arise about their child's future. This may occur when the familiarity of their unspoken expectations for their child is stripped away upon discovering that their child is deaf, and no alternative, positive perspective becomes available to help them envision a positive and realistic future for their child.

As noted in the review, Beaurain (1996, pg.10) and Levitz (1991, p.13) feel that it is not audiological deafness per se which affects the child's development as a person or results in developmental difficulties, but the context within which the child comes to experience him or herself as a Deaf person. Parents and the family, as the child's primary reference point in the world, need to be supported emotionally and practically to enable them to celebrate their child as a whole person, rather than to focus only on deficits and losses.

#### **10.4.1.2                      *Understanding language development***

Language development follows a fairly consistent pattern in children across the world, including young children communicating in Sign Language as a first language. Language is the means whereby the child learns to think, make sense of, and communicate its world to itself and others (Meadows, 1980). It is also the primary means by which parents are able to engage their children, and through which children come to experience themselves relative to their primary caregivers.

#### **10.4.1.3                      *Understanding the child's deafness***

Hearing parents and hearing health providers' knowledge of the deaf child's hearing loss is inferred knowledge. It lacks true understanding of their child's lived experience of deafness. None of the parents seemed to have a clear understanding of the degree of their child's deafness and its relation to what the child could or could not hear, the permanency of the impairment, and the actual effect of hearing aids on their child's ability to detect sound.

Parents need assistance to understand their child's functional range of hearing, as detected by audiograms, so that they can better understand the child's ability to comprehend speech and other sounds, or to learn to produce comprehensible speech (Meadows, 1980). Luterman (1979) found that parents in his educational programmes needed an average of one year after the child's diagnosis to develop the emotional capacity to manage the news and have a good, working understanding of audiological terms and their child's hearing loss profile. He recommended regular, informal reviews

with the audiologist and the inclusion of this information as part of a parent support programme.

#### **10.4.1.4      *The impact of cochlear implants on parental choice***

Although none of the parents in this group had been exposed to the option of cochlear implantation, this will become an option which more parents may want to explore for their children (McCormick, 2003). However, more recent advances in (digital processing) hearing aid technology also show gains for children with profound hearing loss. This calls for new comparative research of the efficacy of the two technologies for communication outcomes for children, and careful consideration in selection of candidates for cochlear implantation. Perold (1999) also notes the importance of counselling for parents to ensure that parents accept their child's deafness, and see the procedure as offering auditory assistance rather than a cure for deafness.

#### **10.4.1.5      *A personal viewpoint on communication***

My own view is that the teaching of Sign Language as early as possible would maximise parental efficacy and enjoyment of their child, thereby promoting sound parent child relationship, as well as starting language acquisition in the child as early as possible<sup>35</sup>.

Sign Language would be the most accessible language to promote language, cognitive and emotional development for the deaf child. The child should be able to experience a sense of agency and mastery as it acquires this language. The child will be able to use it to create a meaningful framework for understanding the world, as well as a tool for growing emotional connections between itself and significant others in the family. Experience of success with Sign Language would provide a secure base for the acquisition and understanding of the more difficult-to-acquire spoken language. As aptly put by Stokoe (Marschark & Clark, 1993, pg 366): "Much of the engineering task of deaf education is *teaching* of language. But language, an individual's first language, has to be acquired by use, by interaction with others."

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<sup>35</sup> The question of access to Sign language training opportunities for families and parents needs to be addressed. In the Western Cape, sign language classes may currently be arranged through the local Deaf organisations and Deaf persons offering sign language course in their individual capacity.

#### **10.4.1.6      *Supporting parental views on language choice***

Parental preferences should at all times be respected and supported (WHO, 1998), including language choices. Most parents in this group wanted their child to learn to speak, based on professional input and on their feeling that speaking would reduce their child's experience of stigma as a deaf person, and help the child to more easily access opportunities in mainstream society. In some cases, Sign language was avoided as parents had been told that this would impact negatively on speech acquisition. A smaller group were happy to have their child learn to sign as well, having been told the contrasting view that their child could learn to speak when slightly older. To enable parents to exercise informed preferences, they should be presented with comprehensive information on choices available to them (National Information Centre on Deafness, 1991) This information should be objectively presented by their practitioner, rather than reflecting only the practitioner's personal perspective.

#### **10.4.2 Coping with additional disabilities**

The questionnaire results do not indicate a vast difference in the stress and difficulty levels experienced by parents with deaf children and those with children who have one or more additional disabilities. Analysis of the interview data also did not yield a particularly strong theme on difficulty in managing children with additional disabilities. These findings are not consistent with literature reported elsewhere in the study. Further, assessment of the mental state of mothers did show a tendency for mothers with additionally disabled children to be stressed or depressed.

These inconsistent findings may reflect higher sensitivity of the questionnaire to stress/difficulties related to deafness specifically (Moore & Meadows-Orlans, 1990), and lower sensitivity to stress/difficulties parents experience as a result of any other disabilities in their child. The lack of specific themes raised in this area from the interview data, may reflect the fact that this theme was not the most dominant area of difficulty for these parents at the time. Poor communication, for example, may be the most obvious issue impacting on their relationship with their child at this time. Parents may prioritise this issue over other concerns about the overall development of the child.

The effects of intellectual and physical disabilities may not be as obviously disabling at a stage when young children are expected to rely on parents for assistance. In addition, for some parents, positive feelings about the likelihood of good progress with their child's *overall* development, was promoted by recent improvements in communication with their child via the acquisition of sign language skills or speech training. Parents also did not seem to have enough information available about their child's physical or intellectual disability to be able to understand or accept its enduring nature. To overcome misunderstandings resulting from having a child with multiple disabilities, practitioners needs to remain attentive to all the child's disabilities when providing support to these parents. The need for a focus on one or more disability at any one time will depend on the needs of the parent at the time.

#### **10.4.3      *Socialising the child***

In chapter nine, parents generally, parents reported coping well with establishing regular routines for their children, such as setting daytime and sleep-wake routine, and teaching self-help skills such as dressing, bathing and eating. These child-rearing activities are largely behaviourally based and parents can demonstrate them practically, as part of the routine others in the family are following.

Problems with child-rearing seemed to relate to parents' difficulties in communicating with the child. This occurred especially when explanations were needed to help the child understand or for parents to understand the child's needs. Potty training and safety measures were difficulty to teach, as children could not understand what their parents wanted. Parents also reported difficulty in communicating family and community norms and practices for socially appropriate behaviour, which is essential to expand the child's understanding of social and behavioural requirements. Parents struggled to know whether poor behavioural compliance from the child was due to poor understanding of instructions or wilful misbehaviour.

Parents understanding of their child's hearing range is important if they are to understand their child's ability to comprehend when engaged in conversation with people with differently pitched voices. For example, it affects the child's responsiveness in

different “noise” situations, their ability to use the phone, to hear the doorbell, etc. Frustrated parents need to know that different situations may be differentially heard by their child, to help them avoid labelling their child as “lazy to hear”, “inattentive” or “naughty”.

#### **10.4.4      *Promoting emotional development***

Expanding Stahlecker's (1983, pg.43) view that interventions with young deaf children focuses on communication and language skills, with little attention to social and emotional development, it is felt that making communication choices for the child should include consideration of its impact on the social, emotional and cognitive development of the child.

Parents of hearing children can easily use verbal *acknowledgements* of a child's presence or needs, verbal *soothers* to contain a child's need for attention, or verbal *links* from tailing off one task occupying the parent's attention, to engaging with new task involving the child. The child is validated, contained and safely directed by the parent's tone, content, and the context of verbal communication. The parent is able to maintain calmness and project a congruent non-verbal message to the child. This reciprocity soothes the child, promotes a sense of self-value and security and assists the child to cope with frustration and build resilience. The continuity of experience promotes the child's temporal reality, giving it a sense of its place in past, current and future experiences (Gregory 1995). Similarly, the native signer or sign- proficient parent is also able to communicate a wealth of information and meaning to the child (Marschark, 1993). The practical ease of teaching the child, and the social and emotional connection provided by the flow of communication between parent and child, may not be as fully experienced by the deaf child where communication is primarily through speaking.

#### **10.4.5 Making educational choices**

18 (80%) parents had not discussed the issue of preschool or formal education with practitioners. This is not surprising given that most of them had only recently been given a diagnosis that their child is deaf.

Most parents were still dealing with the news, relieved at having found some specialised attention to their child's deafness. They were not yet ready to address educational issues beyond the issue of communicating with and learning to cope with their child's needs.

The link between early communication choices and later educational options available to the child in the context of current educational policies and resources is not regularly made with parents when communication choices are discussed. Parents may not be aware of the implications of their choices now, for educational decisions which present later (Beazley and Moore, 1995).

In South Africa, and the Western Cape, each educational facility for deaf children currently applies its own policy on the communication framework within which the child will be educated (Personal Communication 19/01/04, Ms Wilma Neuholdt-Druchen, Personal Communication, Mr Stephen Lombard, 9/02/04), some only offering oral programmes, others applying a total communication philosophy, and still fewer moving to a sign language dominant programme<sup>36</sup>. Mainstream schools also adopt a purely oral approach with deaf children. Currently, there are no sign -able teachers or interpreter services available to deaf children in the mainstream school settings.<sup>37</sup>

#### **10.5 Individual differences: One size does not fit all.**

There are various parent guidance programmes, communication and education strategies and support interventions to promote the deaf child's development. The viability of any one strategy to assist a particular child and family is influenced by a number of issues. These include the child's hearing profile, age, physical and mental

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<sup>36</sup> A task team to address issues related to implementation of sign language in schools will shortly be convened by the Department of Education and DEAFSA (Personal Communication 13/02/04, Ms Wilma Neuholdt-Druchen)

<sup>37</sup> The University of Witwatersrand offers classroom support services for D/deaf students as part of its university programme (Deaf Institute website on the Deaf College). VN Naik, a school for the deaf in Durban, has provided tuition in Sign for the past 17 years, and in 2000 achieved a 100% pass rate for their matriculants for the 4<sup>th</sup> consecutive year. The school now partners with two local colleges for postmatric enrolment of their pupils for teacher training and information technology, and wants to lobby for better access at South African universities for their matriculants as well. The success of the school is attributed to having teachers qualified to teach deaf students, and use of Sign Language for instruction (Bridgraj, 2000).

abilities, the parents' attitude toward and acceptance of the child's deafness, personal preferences for assistance, available family resources and supports, and the availability of and access to services (Luterman 1979). Bailey, et al. (1992) notes that although there may be common trends in the scope of information and support needed by parents, time should be taken to assimilate information obtained from parents and direct work with the child to tailor intervention services for the individual family. Parents and practitioners together need to work toward matching what is needed by the child with what is sustainably available to meet that need.

#### 10.6 Concluding summary

The small number of participants precludes definitive statements about adverse or promotive influencing factors in adjustment and coping of the parents in the study. Nevertheless, the above findings support the contention that assessment and management of healthcare needs should be broadened beyond medical management of the deaf child, to include a focus on overcoming *psychosocial barriers* to parents' providing optimal care for their child. Protective factors which parents already have to assist them to raise their child should be strengthened.

Both *parental and practitioner attitudes* and beliefs influence parental experience of support services offered. Optimal support will require *practitioners* to get to know the context of parental experiences for a particular family, and go beyond his or her theoretical assumptions about what the parent *should* be feeling, to best understand and assist the parents and child. Practitioners need to avoid assuming the inevitability of ongoing, parental sorrow and grief as a result of having a deaf child. They should widen their net of interaction with parents to include support for difficult times, as well as encouragement of positive investment of energy for improving their child's quality of life. Practitioners may find it helpful to be aware of the interaction of parent factors and environmental enablers in creating the enabling or disabling conditions for care of the child: Parents may be supported by working in a cycle of *crisis* (personal/environmental barriers to coping), *support* (personal resilience/environmental resources or opportunities), *adaptation* (deriving a strategy for applying own or environmental resources to reduce or eliminate barrier to coping), *action* (implementing the strategy to



reduce or eliminate barrier to coping) and *crisis* ((re)emerging personal/environmental barriers to coping).

*Parents* are anxious to make the best choices for their (deaf) child. Hearing parents will probably be new to all the options available to them, and may tend to rely heavily on what they perceive to be the expert position and knowledge of the health worker. Health workers should be aware of the potential for this power imbalance, and its seductive ability to incline them toward making decisions for parents, rather than supporting the parent to make their own choices. Health worker training should include a values clarification component which would provide opportunity to clarify their own perspectives on disability (Deaf) issues, so that they are aware of their own and biases when supporting parents.

*Parents experience of health services* indicate that delays in identification and diagnosis of deafness remain a barrier to optimal care. This can be a serious constraint to early intervention with children and their families. Early awareness that the child is deaf, can to promote the parent-child relationship by providing an explanation for the child's frustrating non- reactivity to verbal communication. Late detection delays the introduction of alternatives for starting appropriate language acquisition and improving communication with the child.

Communication is central to all aspects of *child-rearing*. It is recommended that practitioners provide parents with comprehensive information on *communication options* for the child, and support parents to arrive at and follow-through on their choice of communication. (Deyo and Gelzer, 1991). Professionals need to exercise care not to offer one or the other as the *better* option, but rather to focus on the option which is best for the child and family. Although emphasis is placed here on the issue of language choice, the principle outlined applies to all decisions which affects the child and family: The role of the professional is to provide information and support to parents to develop confidence to make informed decisions, and the role of the parent is to make final decision on behalf of themselves, their child and their family. A good understanding of the child's hearing profile can assist parents to know which strengths can be harnessed,

and what is possible for the child with and without properly fitted hearing aids<sup>38</sup>, so as to avoid unnecessary tension between parent and child in the daily enterprise of child-raising.

For parents and child to be able to communicate around day-to-day activities has value in itself in terms of socialising the child within the family, but it has a much wider role in terms of promoting child's sense of self, emotional resilience and overall development as a person.

Finally, communication choices made by parents have a direct impact on later educational options available to the child because of current educational policies on availability of resources for supporting the deaf child in the classroom. As parents are most often exposed to communication options within the health sector, as their first point of service, it is crucial that links between health worker services to deaf infants and preschoolers and the educational sector be strengthened to offer families seamless services for their deaf child.

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<sup>38</sup> The "goodness of fit" of the hearing aid prescription, training in the proper use and maintenance of the hearing aid, assisting the child to adjust to the wearing of the hearing aid, both from a physical and social point of view, and having a good understanding of the limitations of amplification provided by the hearing aid, are all important factors for family and other caregivers to consider.

## **Eleven**

### **Recommendations**

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*What must tell you, me find bad news. Father very sick, hospital, heart. Deaf part of me think deaf way. But me live in hearing world, having hearing roommates, have hearing friends. All act like hearing people. At my house, hearing house. Me sit by phone. Alone. What happen when me tell hearing roommates, they walk out of room. Me find out hearing people think, something happen, your private business. Not ask questions. Leave you alone. Think if you want to talk, you talk they listen, but not ask questions. Me call hearing friends, please come over, need see you. One hearing friend say, busy, but give phone support. Other hearing friend say, I have this block of time. Hearing time. This little block of time. Deaf way very different. Deaf come. In your face, ask ask ask. Want to know everything. A to Z. Important touch. We sit down. Discuss, group. Face to face....*

Rachel, hearing daughter of Deaf parents, signing to other adult children of Deaf, as quoted by Paul Preston: In *Mother Father Deaf*, 1994, page 222.

#### **11.1 Introduction**

The information obtained from this study is used in this section to make recommendations for service development which is affordable within current structures and resources available within the public health sector.

The key recommendations suggested are:

- development of a comprehensive service for deaf children,
- improving assessment, detection and diagnosis of deafness in young children,
- equipping health workers for effective communication with parents,
- developing cost effective options for providing emotional support,
- improving parents access to available financial and social support,

- development of locally informed guidelines for assisting parents and service providers in communication choices,
- preparing parents for educational choices,
- learning from the experience of adult Deaf,
- providing opportunities for improving parenting skills, and
- developing a local research agenda for improving services for the deaf child.

Each of these recommendations are elaborated below:

## **11.2 Development of a comprehensive service for deaf children**

### **11.2.1 *Comprehensive individualised intervention plans for families***

Results suggest the need for a comprehensive support service to deaf children and their families. This service should include medical support, a habilitation programme for children and multi-disciplinary psychosocial support for the child and family. Interventions should incorporate a child-centred programme for children, parent-centred, individualised family work, parent support groups, and parent education and guidance programmes. Local centres of excellence should be identified to assist in modelling comprehensive programmes sensitive to current human and financial resource constraints within the public service. Programmes which utilise innovative means of supplementing available income from the public purse should be identified.<sup>39</sup>

### **11.2.2 *A comprehensive, integrated health service package for the deaf.***

The WHO report (1998) provides an outline of the scope of the service from community to specialist care in the health sector. The report describes the focus of the service, core competencies and training for workers at each level of care for the prevention of ear and

<sup>3939</sup> The comprehensive programme offered at Carel du Toit, a local resource in the Western Cape, where all aspects of the child's medical, family, communication and educational programme is integrated, with outreach to less resourced areas, provides one example of excellence in the development of a local comprehensive service for deaf children (Personal Communication, Meryl Glaser 13/02/2004). The centre is government subsidised but sources private funds as well. Currently, this particular centre's core programme focuses on an auditory aural programme for preschoolers, with sign language users referred to other school programmes. Equitable access to comprehensive programmes should be considered in developing services so that they are available to children who are orally streamed and children who are sign language users.

hearing problems. This model focuses on a framework for service for *preventing* hearing impairment in those who can hear or are at risk for hearing loss, *and* for supporting those who are deaf. It would be most useful if it were expanded to also include a focus on treatment, care and support to the child (or adult) who is *diagnosed as deaf* in the service. Table Fifteen diagrammatically briefs the model proposed by the report, and expands (see italics) on the model to include services to the deaf and their caregivers within the health sector.

### **11.2.3 Intersectoral considerations**

In order to provide a comprehensive individualised intervention plan for families, service providers also need to be enabled to work intersectorally. A more complete service model would therefore need to include a focus on the educational and social service sectors' contributions to services for the deaf child and family, and how these three key sectors may integrate their contributions for a comprehensive service, an exercise beyond the scope of this study.

## **11.3 Improving assessment, detection and diagnosis of deafness in young children**

The importance of appropriate assessment tools and capacity for accurate screening, preliminary diagnosis and accessible follow up and support service at local clinics and specialist units cannot be overemphasised. Barriers to early detection or diagnosis identified in the study suggest interventions at two levels:

### **11.3.1 Parents**

Parental detection and help-seeking behaviour may be improved by public awareness and health education programmes on the signs and symptoms of deafness in young children. Destigmatisation of deafness and inclusion of Deaf cultural issues in the public arena can help improve parental knowledge about deafness, and motivate help-seeking behaviour (Child Health Institute, November 2003).

Information to improve new parent's knowledge of normal child development and the signs of deafness can be included as part of the services parents receive at their well baby clinics. This would assist new parents to be more alert to potential problems their baby may be experiencing.

### **11.3.2 Clinic and hospital health workers**

Health worker knowledge and training in early detection and follow-up of risk factors for deafness (See chapter one) and the proper use of screening tools and parental information can improve detection rates (WHO, 1998). Detection by health workers may also be improved by reviewing the effectiveness of the implementation of current screening and assessment processes:

- Clinic and hospital health workers should be sensitised to the need to foster a "disability –friendly" atmosphere at the clinics to help destigmatise disability and create a safe environment for parents to disclose their child's difficulties.
- Practitioners need to see parents as partners in the child's health care, and give sufficient weighting to ongoing parental observations at home as opposed to their limited professional assessment at clinic appointments.
- The use of unreliable methods should be reviewed, and improvements effected in the application of the screening tools.
- Fast-tracking assessment and follow up appointments of children at risk for or suspected of hearing loss who present with ear infections which preclude reliable diagnosis on the first visit.
- Mental wellness screening should be offered as an integrated part of the overall service to parents. Undetected mental health problems can impede detection and follow-up of suspected deafness, and parental adjustment to and coping with the needs of their deaf child.<sup>40</sup> Parents identified through this process should be referred for further mental health assessment, management and support as required.

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<sup>40</sup> The provincial developmental screening tool includes screening questions for mental health, but it is unclear to what extent this is used effectively by the busy health worker at the clinic. Health workers at other levels of care also need training to be able to include mental health screening as part of their interventions with parents. The province has a mental health service available at clinics and community health centers as part of the integrated primary health care service (Mental Health Programme, 2004).

- Assessment and improvement of the effectiveness of training in the use of screening tools in primary health care is necessary, as demonstrated in the recent evaluation of the current developmental screening process in the WCP (Children's' Institute, November 2003).
- Monitoring of the implementation of training for routine screening at clinic visits, according to protocol, as part of the provincial developmental screening process (Children's' Institute, November 2003).
- Ensuring that essential equipment is in working order at all sites.

### **11.3.3 Affordability considerations**

Given the limited success enjoyed by the implementation of the developmental screening programme launched in the WCP due to capacity constraints (Child Health Institute, November 2003)<sup>41</sup>, the new health plan in the WCP is well-timed. It proposes an increased emphasis on ensuring quality primary health care, and strengthening capacity, both human and infrastructural, at primary, secondary and tertiary levels of care (Healthcare 2010, October 2002). The recommendations of the 2002 Hearing Screening Position Statement of the Professional Board for Speech, Language and Hearing Professions (Health Professions Council of South Africa, December 2002) recommends a comprehensive approach to targeted (risk based) newborn hearing screening (TNHS). An Early Hearing Detection and Intervention Programme (EHDI) to reduce the age of identification, diagnosis and intervention for deaf children, sets laudable goals. However, these would need extensive further deliberation in terms of the feasibility of implementation and development of a step wise and sustainable implementation plan, within available resources.

### **11.4 Equipping health workers for effective communication with parents**

Chapters Six and Ten outline several barriers to effective communication with parents. The health worker's approach to communicating would need to be sensitive to these difficulties to be effective. Clear communication to parents regarding the process,

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<sup>41</sup> The evaluation report produced by the Child Health Unit notes that these finding are in keeping with other recent evaluation reports on child health programmes, in the WCP, and is not an isolated trend.

testing, findings, and issues related to the diagnosis and further care of the child should include the following:

- a non-discriminatory, enabling and supportive approach by the health worker in communicating the news,
- access to someone who is able to communicate the important aspects of the work with the child to the parent in a language he or she understands,
- communication in everyday easily understandable language, as far as possible
- where technical information is provided, explanations to parents in non-technical terms as well to promote understanding,
- checking on parent understanding of the current status of information about their child, particularly when multiple providers work with one family. Parents may need to be told the same news several times, in different ways, at subsequent appointments to help them to process the news, overcome avoidance or denial of the news, and to correct misunderstandings,
- ensuring continuity of service by efficient written communication for other health workers regarding what has and has not been communicated to parents, given that the service may involve many practitioners working with one family.

A focus on communication skills during diagnostic, treatment and psycho-educational interactions with parents of deaf children, should be included in basic and in-service training of health workers.

## **11.5 Developing cost effective options for providing emotional support**

### **11.5.1 *Individual and group counseling or parent guidance programmes***

Brief, focused, supportive individual or group counselling should be available. Parent support groups may be facilitated by professionals or trained laypersons or by parents offering peer support, as resources permit. These services should:

- assist parents to deal with the shock of the diagnosis, and subsequent, episodic periods of stress as new challenges need to be addressed,



- contextualise the normality of their feelings of fear, anger and concerns, and increase understanding that these feelings, and their desires for best outcomes for the child are not mutually exclusive,
- provide parents with opportunity to express and process their emotions within a safe, contained environment,
- provide a space within which parental strengths and resilience can be supported, their options can be explored and their use of available resources can be optimised,
- assist the health worker to detect gaps in the parent's knowledge and to provide parents with accurate information,
- assist the health worker to identify barriers to optimal care for the child. In this study group, for example, the researcher was able to detect several depressed mothers, who were struggling to cope with their child, and who needed additional referral for mental health treatment and support, and
- provide opportunity for parenting skills training and support to cope with the challenges of managing the child's day to day routine and behaviour

#### **11.5.2 *Creating affordable and sustainable options for support***

In the public sector options for these additional services may be limited, but not impossible to develop, according to resources: For examples, where available, state or NPO-based social workers could assist with counseling. Where fewer resources are available, peer-run groups can be developed to provide an environment of mutual support for parents. With the recently diagnosed deaf child, early intervention is important to assist parents onto helpful tracks, and this should be offered within walking distance of families' homes. Support groups and clubs are already run at clinics for chronic diseases of lifestyle such as hypertension, epilepsy and other conditions with long-term health consequences. A similar concept for the psychosocial support of children and families managing disabilities, including deafness, could be set up at clinics.

In the absence of readily available staff to run groups at times, clinics can be assisted by the development of appropriate learning materials for use in the groups. For example, five parents in this study reported that the television programme SignHear, a magazine

programme hosted in Sign Language, was their first contact with the Deaf community. This programme presents Deaf issues in an accessible and socially appropriate way, helping to diffuse stigma and myths attached to being deaf and providing a window to the world with which they and their child would now need to engage. Three parents noted that their acceptance of Sign Language as an option for communication for their child was influenced by their exposure to the language on this television programme. Video material such as this could be developed for group use to highlight key issues, and for teaching basic Sign Language skills. Where clinics do not have video access, taped discussion inserts and written material can also be used. In areas with high levels of illiteracy, written material can be developed in pictorial form to aid discussions.

Resource-sensitive means of extending this concept to the broader population would need further development and feasibility study beyond the scope of this study. These suggestions are briefly mentioned here, to demonstrate that while the service offered to the study participants currently reaches a limited population, the concept of providing a holistic one-stop service for the deaf child and parent is not impossible. Such a service should include assessment, diagnosis, treatment, rehabilitation and psychosocial support.

#### **11.6 Improving parents access to available financial and social support**

Service development issues which need to be addressed to support parents and reduce their burden of care include the following:

- economic screening, and informing parents of their eligibility for child care support,
- financial support, including access to available financial assistance for childcare, such as the childcare grant,
- attention to the fact that parents need to be able to access services as close to their homes as possible, to increase the likelihood of attending and to reduce costs for indigent users who have to travel to a special clinic, and
- appropriate day care services for the deaf child, to enable mothers to retain or seek employment.

### **11.7 The development of locally informed guidelines for assisting parents and service providers in communication choices**

There are a variety of strongly held positions experts promote with regard to language and communication choices for deaf children. Some recommend a strictly oral programme for the child, others recommend that parents focus on Sign Language as the child's first language, while others advocate teaching Sign *and* supporting the child to learn to speak as far as is possible. This can be most confusing for parents and, as communication is a key consideration for parents in caring for their child, this issue requires *concerted* deliberation from the adult D/deaf, professionals and other relevant sectors. This would not necessarily resolve this age old debate (Winefield, 1987), but at best provide clear guidelines on how best to work with parents to safely negotiate this minefield in making informed decisions for their child. Parents' choices are significantly influenced by available resources, and a local analysis of our situation, and affordable ways for improving options available to parents and their children would be beneficial.

#### **11.7.1 *Balancing health worker expertise with parent rights***

Some practitioners still choose to promote the perspective they have evaluated as best for the child, reasoning that parents are confused, stressed and need directive guidance on the appropriate choice. This view is paternalistic and denies the parents' right to make fully informed decisions for their child. Communication choices *are* difficult to make for the parent of the deaf child. Instead of removing parental choice by punting a particular perspective, parental anxiety should be acknowledged and reduced by supporting parents, through the provision of accessible, but comprehensive information on all available options, as soon as possible. Parent education programmes on communication choices for their child should provide them with an overview of all options available to their child, inclusive of hearing and Deaf perspectives. The emphasis should be on early detection, early diagnosis, and early assistance for parents.

### **11.8 Preparing parents for educational choices**

The importance of the impact of early communication choices on the availability of educational choices within the local context should be addressed with parents. Parents

should be assisted to address this issue with sufficient time to benefit from exposure to the whole range of available options for their child, preferably via visits for first hand exposure, otherwise through videos, information pamphlets and presentation, as resources permit. Parents' task would also be made easier if there was improved coordination between service providers, with the aim of promoting a seamless transition of the child from home, to preschool, primary school, high school and other vocational and tertiary educational opportunities.

### **11.9 Learning from the experience of adult Deaf**

Additional inputs on their experiences from other parents of deaf children and adult members of the Deaf community would provide parents with valuable retrospective opinions on the potential outcomes of their present choices for their children. The inclusion of the experience of Deaf adults, via videos, pamphlets, or presentations, would improve the quality of psycho-educational programmes offered to parents. The appointment of Deaf practitioners should also be encouraged in clinical support programmes for parents of deaf children. DPSA (Pg 7, 2000) emphasises the need to recognise that people with disabilities may also be experts in the field of disability.

Exposure to successful Deaf role models can also provide parents with experiences to support the potential for a successful future for their child. In this study, other than the sign language teacher, parents' experience with Deaf role models was limited to deaf people in television programmes, or a deaf colleague or neighbour. None of the parents had been introduced to the local Deaf organisations and the support services they provide.

It is felt that psycho-educational programmes for parents would benefit from the inclusion of inserts from Deaf adults who have experienced speech training, sign language training, cochlea implantation and other issues of concern to the parents. This should broaden their knowledge and understanding of the lived Deaf experience and assist them to make more informed decisions, within the resources available to them.

### **11.10 Providing opportunities for improving parenting skills**

Parents should be encouraged to be actively involved as part of the team planning interventions for the child. Parents have intimate knowledge of the child which can assist the intervention team to present viable options or choices for consideration in assisting the child. They are well-positioned to provide valuable feedback on whether interventions are having the desired effect, and also serve as the primary enabler of all interventions planned for the child.

It is important then, for parents to be enabled to participate in decisions and planning to overcome any barriers they and their children may experience. Parents will be better able to participate if informed about issues relevant to them and their deaf child. Parent educational material, information sessions, lectures or counselling should be presented in simple accessible language, free of professional jargon, and aimed at increasing parents' confidence and capacity to care for their child (Marshark, 1993, pg 35).

There is a wide range of available material to inform the development of a basic, but comprehensive set of health promotion and health educational materials and programmes for use by service providers in their work with parents. Table Sixteen summarises some of the key areas suggested by research from which parents may benefit in an educational programme (The Elizabeth Foundation (website), Levitz, 1991, Marshark, 1993, WHO, 1998, Adams, 1998, Richter, 2001, The National Deaf Children's Society, 2003).

### **11.11 Developing a local research agenda for improving services for the deaf child.**

Each of the above recommendations for improving services to parents and their deaf children suggests areas for local research to inform the development of strategies and implementation guidelines best suited to the South African situation.

Attention to local research with adult Deaf is also needed to assess the impact of choices made by their parents when they were babies and young children, on their own

lived experience as Deaf people. Their views on their satisfaction with language choices made for them by their parents, health providers and educationalists, for example, would be one area of focus. Such research would provide valuable insights about the most appropriate directions in which to develop services, as well as giving health workers and parents guidance in assisting parents to make choices for their young children in the clinical exchange.

- Research on protective and mediating factors which may assist parents to cope with their deaf child within the local context would also contribute to service development for the parents of local deaf children.

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**Table 15** Primary Ear and Hearing Care, and Disability Prevention Programme for the Deaf (Adaptation: WHO Report on Ear and Hearing Care, Page 5, 1998, Maternal Child and Women's Health Programme, 1999 and 2001 Hearing Screening Position Statement, Professional Board for Speech Language and Hearing Professions, HPCSA, 2002).

Level of Intervention	Interventions	Target Provider
<b>Level 1(a)</b> <b>Community</b> The general community and its organisations	Posters, pamphlets, radio, videos, drama, talks, campaigns for awareness raising, health education and health promotion on ear and hearing care, the prevention of hearing problems through safe ear practices and early intervention for ear disease, the <i>prevention of stigma and disability, the promotion of inclusion of Deaf persons in the broader community, and of organizations for the promotion of Deaf culture and deaf interests.</i>	Family, (pre)school community (teachers/children/governing body), health committees, social service and education structures, community based organisations (CBOs), including <i>D/deaf CBOs</i> , faith-based organisations (FBOs), non-profit organisations (NPOs), including <i>D/deaf NPOs</i> , community and business places
<b>Level 1(b)</b> <b>Community</b> Community Health Workers (CHWs) or Health Promoters (HPs)	Disseminate health and health education information to parents and the community on the prevention and treatment of hearing problems <i>and available support and community services for D/deaf persons and their families</i> Encourage community action regarding a safe environment for the promotion of hearing and prevention of hearing impairment, <i>and the prevention of stigma and disability for D/deaf persons.</i> Identify children/adults at risk for hearing problems & refer for assessment <i>Identify deaf/hard of hearing children and adults at risk for disability and provide or refer for support to other services (healthcare, financial and other social support, D/deaf organisations, etc).</i> To provide basic treatment <i>and support</i> as appropriate. To support patients <i>and families</i> in treatment compliance. To support families of <i>D/deaf</i> to strengthen personal resources and access other available resources necessary for community integration.	CBOs, FBOs and NPO's with community workers (or home based carers) <i>Sign Language Practitioners and specialist NPOs working for the D/deaf</i> Traditional healers.

**Table 15 continued: Primary Ear and Hearing Care, and Disability Prevention Programme for the Deaf**

<b>Level of Intervention</b>	<b>Interventions</b>	<b>Target Provider</b>
<b>Level 2(a)</b> <b>Primary Health Facility</b> (mobiles, satellites, and community health centers (CHCs))	Provide support to and work with CHWs. Screening to identify deaf/hard of hearing children and adults Assessment, diagnosis, and treatment of common ear and hearing ailments, and referral for medical/specialised care as per protocol. <i>Provide or refer deaf/hard of hearing caregivers and adults for support to other services (healthcare, financial and other social support, D/deaf organisations) to prevent the disabling effects of deafness.</i> Provide follow up care and support as required.	Primary Health Nurse Health Promoters
<b>Level 2(b)</b> <b>Primary Health Facility/Service</b>	Support and train PHC practitioners at level 2(a) Screen, assess, diagnose, and treat hearing ailments. <i>Fast-track follow-up of at children and adults at risk as per protocol.</i> Refer for specialised services and coordinate specialist clinics. Develop family centred awareness, prevention, rehabilitation and disability prevention programmes for the community in the drainage area of the CHC.	Clinical Nurse Practitioners PHC Nurse with Special Training in area of Hearing Care at CHC Medical Officers
<b>Level 3</b> <b>District or Secondary Hospitals</b> Programme management, specialised service and specialist sessions	<i>Assessment, treatment and habilitation/disability prevention plan for hard of hearing and D/deaf via specialist (outreach or onsite as capacity allows) clinics to outlying areas.</i> <i>Devise, implement and monitor needs for training on a local level to develop capacity of and support staff in the region.</i> <i>Support the development of education and support programmes for caregivers and families.</i> <i>Coordinate information required to monitor service development.</i>	Medical Officers with ear and hearing care training, and if possible, ENT, Audiological and Speech and Language Service and social work service at district/regional hospital. Regional Information manager and human resource practitioners.
<b>Level 4</b> <b>Tertiary Hospitals</b> Specialist Service	Specialist Assessment. Treatment, Habilitation/Disability Prevention Plan for Hearing, Hard of Hearing and D/deaf. Consultant clinical support, support for the development of training programmes, protocols and guidelines for ongoing capacity development of generalists.	ENT, audiological, communications, and rehabilitation practitioners, social work services, medical and surgical specialists
<b>Provincial Office</b>	Policy development, monitoring & evaluation, information system and quality assurance	Provincial Programme Managers for MCWH, Quality Assurance and Information Management



**Table 16:**                    **Some basic elements for inclusion in a support programme for parents of deaf children**

<b>Awareness, Health Education and Health Promotion</b>
<p>Written, taped or video-taped educational material, information sessions, "Mommy-and Me" peer groups for information on:</p> <p>Ear and hearing care  Child development education, including hearing development  Risk factors for and warning signs of hearing impairment in the young child  Available screening services for children and support services for the parents of a Deaf child  Prevention of stigma and disability, and the promotion of positive attitudes toward Deaf people and issues  Encouraging parent action regarding the prevention of stigma and disability for Deaf persons  Information on Deaf cultural issues</p>
<b>Early assessment and diagnosis</b>
<p>Provide parents with information on:</p> <p>New terminology and concepts related to deafness (explaining common terms).  The nature and degree of the child's hearing threshold profile.  Communication Choices: Preliminary information of the implications of the hearing loss for communication options for the child.  Training parents in the care of the child's ears where ear disease is present.  Understanding the scope and limits of hearing augmentation and amplification (lip reading, hearing aids, cochlea implants, etc) and training in the proper use, care and repair of aids.</p>

**Table 16 cont'd:      Some basic elements for inclusion in a support programme for parents of deaf children**

Support
<p><b>Personal resources:</b> Supporting and Improving parents' mental health and resilience</p> <p><b>Emotional support resources:</b> Family and community support, parent support groups and counselling services</p> <p><b>Communication support Resources:</b> Information on language development in the hearing and deaf child. Oral, Sign and Total Communication perspectives, assistance in choosing options for their child, and information on services available to exercise these choices</p> <p><b>Environmental resources:</b> Family income, financial support, access to services for healthcare, social support, respite services.</p> <p><b>Educational Resources:</b> Oral, Sign, Total communication, mainstreaming and special needs (pre) schools</p> <p><b>Deaf resources:</b> Access to local deaf services, organisations and Deaf adults</p>
Parenting Skills
<p>Understanding the child's deafness in the context of the child's overall physical and mental health status.</p> <p>Understanding the impact of additional disabilities on child's overall physical and mental health status, and strengthening parents' ability to cope with the child with multiple impairments.</p> <p>Understanding the deaf child's behaviour in the context of being deaf: Being more "physical" in communication and relating, watching body and nonverbal cues to understanding, etc.</p> <p>Basic behaviour management skills.</p> <p>Teaching nonverbal, visual and physical ways of communicating with the child.</p> <p>Teaching family norms and expectations.</p> <p>Promoting the child's emotional and social development.</p> <p>Discipline and limit-setting.</p> <p>Establishing a bedtime routine, potty training and other self help skills.</p> <p>Safety considerations for the deaf child.</p> <p>Coping skills for parents.</p> <p>Stress management</p> <p>Crisis management</p>

## References

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- Adams, J. W. (1988). *You and your hearing impaired child: A self instructional guide for parents*. Washington, DC : Gallaudet University Press.
- Ainsworth, M. D. S., Blehar, M., Waterson, E., & Wall, S. (1978). *Patterns of attachment: A psychological study of the Strange Situation*. Hillsdale, New Jersey: Erlbaum.
- Allen, D. A. & Affleck, G. (August 1985). Are we stereotyping parents? A postscript to Blacher. *Mental Retardation*, 23 (4), 200-202.
- American Psychiatric Association. (1994). *Diagnostic and Statistical Manual of Mental Disorders*. (4<sup>th</sup> ed.). Washington DC: American Psychiatric Association
- Bailey, D. B., Blasco, P. M. & Simeonsson. (1992). Needs expressed by mothers and fathers of young children with disabilities. *American Journal on Mental Retardation*, 97(1), 1-10.
- Beaurain, M. (1996). *Deafness and psychiatric disorders: Personality versus personality disorders*. Conference proceedings: Deaf psychiatry symposium and skills training conference, Institute for the Deaf, Worcester, South Africa, 11-14 June 1996.
- Beazley, S., & Moore, M. (1995). *Deaf children, their families and professionals: dismantling barriers*. London : David Fulton Publishers.
- Beresford, B. A. (1994). Resources and strategies: How parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry*, 35, 171-209.
- Bridgraj, A. (2000). *Deaf, not Dumb*. The Teacher: Mail and Guardian, Johannesburg, South Africa.
- Bowlby, J. (1988). *A secure base. Clinical applications of attachment theory*. London: Routledge.

Carel du Toit Centre, (undated pamphlet). *Preschool habilitation program for deaf children at Tygerberg Hospital*. Cape Town, South Africa.

Child Health Unit. (December 1999). *HARK (Western Cape) Progress Report*. Department of Paediatrics and Child Health, University of Cape Town, South Africa.

Cohen, L.H. (1994). *Train Go Sorry. Inside a Deaf world*. Boston, New York : Houghton Mifflin Company.

Creswell, J.W. (2003). *Research Design. Qualitative, Quantitative, and Mixed Methods Approaches* (2<sup>nd</sup> ed.). London: Sage Publications.

DEAFSA. (1995). Deaf in South Africa. *BUA!* 10(1). National Language Project, Salt River, South Africa.

Densham, J. (1995). *Deafness, children and the family: A guide to professional practice*. England : Ashgate Publishing Limited.

Department of Health. (1999). *Health Sector Strategic Framework, 1999 –2004*, National Dept of Health, Pretoria, South Africa.

Department of Health (PAWC). (December 1999). *Developmental Screening Tools*. Provincial Administration of the Western Cape, South Africa.

Department of Health (PAWC). (October 2002). *The Case for change! A brief introduction to Healthcare 2010, a conceptual framework for change*. Provincial Administration of the Western Cape, South Africa.

Department of Health (PAWC). (2003). *Healthcare 2010: Strategic plan for health in the Western Cape Province*. Provincial Administration of the Western Cape, South Africa.

Department of Health (PAWC). (unpublished draft, February 2004). *Proposed mental health and rehabilitation service package: From primary health care to psychiatric hospitals in the Western Cape*. Mental Health Programme, Department of Health, Provincial Administration of the Western Cape, South Africa.

De Vos, A.S. & Fouche, C.B. (1998). General introduction to research design, data collection methods and data analysis. In: A.S. de Vos. (Ed.). *Research at grass roots. A primer for the caring professions*. pp. 76-94. J.L. van Schaik Publishers, Pretoria, South Africa.

De Vos, A.S., & van Zyl, C. G. (1998). The grounded theory methodology. In: A.S. de Vos. (Ed.). *Research at grass roots. A primer for the caring professions*. pp. 265-276. J.L. van Schaik Publishers, Pretoria, South Africa.

Deyo, D., & Gelzer, L. (1991). When a hearing loss is diagnosed. In *Growing Together: Information for parents of deaf and hard of hearing children (2<sup>nd</sup> ed.)*. National Information Centre on Deafness, pp. 1-8, Gallaudet University Press, Washington D.C.

Disabled People South Africa. (2000). *Pocket guide on disability equity. An empowerment tool in support of The Africa Decade Of Disabled Persons: 1 January 1999 – 31 December 2000*, DPSA Parliamentary Office, Cape Town, South Africa.

Farkas, M.D., & Anthony, W. (eds.). (1989). *Psychiatric Rehabilitation Programs: Putting theory into practice*. Baltimore: The Johns Hopkins University Press.

Glazer, B.G., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Chicago: Aldine.

Frazier-Maiwald, V., & Williams, L. M. (1999). *Keys to raising a deaf child*. Hauppauge, New York: Barron's Education Series.

Gelzer, L. (1991). Growing Up: Discipline, Behaviour, and Emotional Development. In National Information Centre on Deafness, *Growing Together: Information for parents of deaf and hard of hearing children (2<sup>nd</sup> ed.)*, pp. 9-12, Gallaudet University Press, Washington, D.C.

Gergen, M. M. (1988). Narrative structures in social explanation. In C. Antaki (ed.), *Analysing everyday explanation: A casebook of methods*, pp. 94-112, Sage Publications Ltd, California.

Gibbin, K.P., O'Donoghue, G.M., & Nikolopoulos, T.P. (2003). Medical and surgical aspects of paediatric cochlear implantation. In: McCormick, B., Archbold, S. (eds.). pp. 135-161, Whurr Publishers Ltd, London, UK.

Greenspan, M. (1998). "Exceptional " mothering in a normal world. In: C.G. Coll, J. L. Surrey, & K. Weingarten. *Mothering against the odds. Diverse voices of contemporary mothers*. New York, New York: The Guilford Press, pp 37-60.

Gregory, S. (1995). *Deaf Children and their Families*. London : Cambridge University Press.

Grinnell, R.M. (Ed). (1985). *Social work research and evaluation (2nd ed.)*. Illinois: Peacock Publisher.

Hall, B. L. (1981). The democratisation of research in adult and non-formal education. In: P. Reason, & J. Rowan (Eds.). *Human Inquiry. A sourcebook of new paradigm research*. pp. 447-456. John Wiley and Sons, Ltd, The Bath Press, Avon, Great Britain.

Hardy, R. E., & Cull, J.G., (1974). *Educational and Psychosocial Aspects of Deafness*. Springfield, Illinois, USA : Charles C. Thomas Publishers.

Harris, J. (1995). *The cultural meaning of deafness*. England: Ashgate Publishing.

Hayley, J. (1981). *Uncommon Therapy*. New York: Norton.

Hewson, D. (1997). Coping with Loss of Ability: "Good Grief" or Episodic Stress Responses? *Social Science Medical*, 44 (8). pp. 1129-1139.

Holmes, J. (1993). *John Bowlby and Attachment Theory*. London: Routledge.

Hudelson, P. M. (1996). *Qualitative Research for Health Programmes*. Geneva: WHO.

Ivey, A. E., & Simek-Downing, L. (1980). *Counseling and Psychotherapy*. Englewood Cliffs, N.J., USA : Prentice-Hall.

Janesick, V. J. (1992). Ethnic and Cultural Considerations. In T.N. Kluwin, D. F. Moores, & M.G. Gaustad. (Eds)., *Toward effective public school programmes for deaf students: Context, Process and Outcomes*. pp. 49-65, Teachers College Press, New York, New York.

Kisor, H. (1994). *What's that pig outdoors? A memoir of deafness*. Canada: Harper Collins Canada.

Kubler-Ross, E. (1969). *On death and dying*. New York: MacMillan.

Levitz, A. (1991). *A parent guidance programme for the education of deaf children*. Doctoral Thesis, University of South Africa, Pretoria.

Luterman, D. (1979). *Counselling parents of hearing-impaired children*. Boston : Little Brown and Company.

Manfredi, M.M. (1993). The emotional development of deaf children. In M. Marschark, & M.D. Clark. (Eds.). *Psychological Perspectives on Deafness*, pp. 49- 63, Lawrence Erlbaum Associates, Hillsdale, New Jersey.

Marsh, D.T. (2000). The family experience of psychiatric disability. In: A.M. Spanoil, D.T. Zipple, D.T.Marsh, & Y. Finley. (Eds.). *The role of the family in psychiatric rehabilitation*. pp. 9-28. Boston: Centre for Psychiatric rehabilitation, Boston University.

Marschark, M. (1993). *Psychological Development of Deaf Children*, New York, New York : Oxford University Press.

Marschark, M. (1993). Origins and Interactions in Social, Cognitive and Language Development of Deaf Children. In M. Marschark, & M.D. Clark. (Eds.). *Psychological Perspectives on Deafness*, pp. 7-26, Lawrence Erlbaum Associates, Hillsdale, New Jersey.

Mather, S. (1990). Home and Classroom Communication. In D. F. Moores, & K.P. Meadow-Orlans. (Eds.). *Educational and Developmental Aspects of Deafness*. pp. 232-254, Gallaudet University Press, Washington D.C.

Maxon, A. B., & Brackett, D. (1992). *The hearing impaired child: Infancy through the high-school years*. USA: : Butterworth-Heinemann, Andover Medical Publishers.

Mayan, M.J. (2001). *An introduction to qualitative methods: A training module for students and professionals*. Alberta, Canada: International Institute for Qualitative Methodology.

McCormick, B. (2003). Assessing audiological suitability of cochlear implants for children below the age of five years. In: B. McCormick, & S. Archbold (Eds.). *Cochlear implants for young children (2<sup>nd</sup> ed.)*. pp. 96-134, Whurr Publishers, London UK.

Meadow, K. P. (1980). *Deafness and Child Development*, London: Edward Arnold Publishers.

Mitchell, M., & Jolley, J. (1996). *Research design explained*. (3<sup>rd</sup> ed.). USA: Harcourt Brace College Publishers.

Moore, H. L. (1996). Mothering and social responsibilities in a cross cultural perspective. In: E. Bortolaia (Ed.). *Good Enough Mothering? Feminist perspectives on lone motherhood*. pp. 58-75, Great Britain, Routledge.

Moores, D. F., & Meadows-Orlans, K.P. (eds.). (1990). *Educational and Developmental Aspects of Deafness*. Washington D.C.: Gallaudet University Press.

Muller, A.M.U., & Wagenfeld, D.J. H. (2003). Cochlear implantation in children under 2 years and between 2 & 3 years: a comparative study. *Communiphon*, Spring 2003, No. 336, 28-30.

National Programme of Action Steering Committee. (May 1996). *National Programme of Action for Children in South Africa*. Government of National Unity, Pretoria, South Africa

Nevins, M. E., & Chute, P. M. (1996). *Children with Cochlear Implants in Educational Settings*. San Diego, USA : Singular Publishing Group.

Nikolopoulos, T.P., Archbold, S., & McCormick. (2003). Current trends in paediatric cochlear implantation. In: B. McCormick, & S. Archbold. (Eds.). pp. 1-9, Whurr Publishers, London.



National Ministry of Health, Republic of South Africa. (April 1997). *White Paper on the Transformation of the health care system in South Africa*. Government of National Unity, Pretoria, South Africa

Office of the Deputy President, Republic of South Africa. (November 1997). *White Paper on an Integrated National Disability Strategy*, Office of the Deputy President, Republic of South Africa.

Office of the Premier, Provincial Government of the Western Cape. (November 2002). *Integrated Provincial Disability Strategy of the Western Cape*, Provincial Government of the Western Cape, South Africa.

Poggenpoel, M. (1998). Data analysis in qualitative research. In: A.S. de Vos. (Ed.). *Research at grass roots. A primer for the caring professions*. pp. 334-353. J.L. van Schaik Publishers, Pretoria, South Africa.

Potgieter, A. (1996). *Deafness and psychiatric disorders: Handicap versus disability*. Conference proceedings, Deaf psychiatry symposium and skills training conference, Institute for the Deaf, Worcester, South Africa, 11-14 June 1996.

Perold, J. L. (May 1999). *An investigation into the expectations of mothers of children with cochlear implants*. Dissertation in partial fulfilment of the requirements for the degree of Master of Audiology, Faculty of Logopaedics, University of Cape Town, Rondebosch, Cape Town, South Africa.

Preston, P. (1994). *Mother Father Deaf*. Cambridge, Massachusetts, and London, England : Harvard University Press.

Professional Board for Speech, Language and Hearing Professions. (December 2002). *Hearing Screening Position Statement Year 2002*. The Health Professions Council of South Africa, South Africa.

Red Cross Children's Hospital Child and Family Unit. (undated). *Diagnostic interview schedule*. Child and Family Unit, Rondebosch, Cape Town, South Africa.

Richter, L. (2001). *Development and implementation of a primary care model to promote interactions between caregivers and young children in the Eastern and Western Cape Provinces*. Directorate Mental Health and Substance Abuse, National Department of Health, Pretoria, South Africa.

Sacks, O. (1990). *Seeing Voices*. London: Pan Books.

Sameroff, A. J. (1993). Models of Development and Developmental Risk. In: C.H. Zeanah. (Ed.). *Handbook of Infant Mental Health*, pp. 3-13, Guilford Press, New York.

Schurink, E.M. (1998). Deciding to use a qualitative research approach. In: A.S. de Vos. (Ed.). *Research at grass roots. A primer for the caring professions*. pp. 239-251. J.L. van Schaik Publishers, Pretoria, South Africa.

Spencer, P. C., & Deyo, D.A. (1993). Cognitive and Social Aspects of Deaf Children's Play. In *Psychological Perspectives on Deafness*. M. Marschark, & M. D. Clark, (Eds.), pp. 365-376, Lawrence Erlbaum Associates, Hillsdale, New Jersey.

Stern, D. (1985). *The interpersonal world of the infant*. New York: Basic Books Inc.

Stern, D.N., & Bruschweiler-Stern, N. (1998). *The Birth of a Mother*. New York, New York: Basic Books.

Stokoe, W.C. (1993). The Broadening and Sharpening of Psychological Perspectives on Deafness. In: M. Marschark, & M. D. Clark, (Eds.). *Psychological Perspectives on Deafness*, pp. 365-376, Lawrence Erlbaum Associates, Hillsdale, New Jersey.

Smuts-Pauw, E. (1996). *Psychotherapy: Hearing Therapist, Deaf Client?* Conference proceedings, Deaf psychiatry symposium and skills training conference, Institute of the Deaf, Worcester, South Africa, 11-14 June 1996.

Stanovich, K. E. (1996). *How to think straight about psychology* (4<sup>th</sup> ed.). USA: HarperCollins Publishers.

Statistics South Africa. (1996). *Census 1996: Census in Brief. Report no. 03-01-11 (1996)*. Statistics South Africa, Pretoria, South Africa.

Statistics South Africa. (2000). *Census 1999 : Results on the Household Survey*. Statistics South Africa, Pretoria, South Africa.

Statistics South Africa (2003). *Census 2001: Census in Brief (2<sup>nd</sup> ed.)*. Report no. 03-02-03 (2001). Statistics South Africa, Pretoria, South Africa.

Taylor, G., & Bishop, J. (1991). *Being Deaf: the Experience of Deafness*. London: Printer Publishers.

The Constitution of the Republic of South Africa, Act 108 of 1996, Republic of South Africa.

The Children's Institute. (November 2003). *Evaluation of the Western Cape Province Screening Programme for Developmental Disabilities in Pre-school Children*. Children's Institute, University of Cape Town, Rondebosch, Cape Town, South Africa.

The Elizabeth Foundation Educational Programmes, (09/01/04).  
<http://www.oraldeafed.org>.

The National Deaf Children's Society. (June 2003). *Parenting and deaf children: Report on the needs assessment study undertaken as part one of the NDCS Parents' Toolkit Development project*. USA: The National Deaf Children's Society.

Van der Merwe, H. (1996). The research process: problem statement and research design. In: J. G. Garbens. (Ed.). *Effective research in the human sciences*. pp. 277-291. J.L. van Schaik Publishers, Pretoria, South Africa.

Western Cape Maternal Child and Women's Health Programme: Provincial Reference Group. (December 1999). *Screening for Developmental Disabilities in Preschool children: 0-6 weeks, 9 months and 18 months screening tools*. Circular No. H159/1999. Department of Health and Social Services, Provincial Administration of the Western Cape.

Western Cape Maternal Child and Women's Health Programme: Provincial Reference Group (September 2001). *Paediatric case management guidelines: Upper respiratory infections/conditions*. Circular No. H93/2001. Department of Health, Provincial Administration of the Western Cape, South Africa.

Winefield, R. (1987). *Never the twain shall meet: Bell, Gallaudet, and the Communications Debate*. Washington D.C : Gallaudet University Press.

World Health Organisation. (1998). *Report of the International Workshop on Primary Ear and Hearing Care*, Cape Town, South Africa, 12-14 March 1998. WHO, Geneva, Switzerland.

World Health Organisation. (April 2002). *Prevention of deafness and hearing impairment*. [http://www.who.int/pbd/pdh/pdh\\_home.htm](http://www.who.int/pbd/pdh/pdh_home.htm)

Zeanah, C.H., Boris, N.W., & Larrieu, J.A. (February 1997). Infant Development and Developmental Risk: A review of the Past 10 Years. *Journal of the American Academy of Child and Adolescent Psychiatry*, 36(2).

## Appendix One

### Language and hearing items in the 6 weeks, 9 months and 18 months Developmental Screening Tool, Western Cape Province.

(D) is meant to indicate a possible developmental problem. The child should be referred for developmental screening if this response applies.

<b>QUESTIONS TO PARENT/CAREGIVER</b>		
<b>0 – 6 WEEK SCREENING TOOL</b>		
Ask: Were both parents of the child born with normal hearing?	Yes	No (D)
Ask: Does the child startle to sound?	Yes	No (D)
<b>9 MONTH SCREENING TOOL</b>		
Ask: Does the child make speech sounds (e.g. ma-ma-ma, da-da) Or try to copy your sounds?	Yes	No (D)
Ask: Does the child turn toward you when you call his/her name?	Yes	No (D)
<b>18 MONTH SCREENING TOOL</b>		
Ask: Does the child respond to simple commands or questions? (e.g. show me your foot/nose; Where is mommy?)	Yes	No (D)
Ask: Does the child use 3 recognisable words?	Yes	No (D)
Ask: Does the child turn toward you when you call his/her name?	Yes	No (D)
<b>PHYSICAL EXAMINATION</b>		
<b>6 WEEKS</b> If there is any doubt, clap hands loudly out of sight of the baby. Observe for blinking, startle reactions or cessation or change in physical activity (for example, stopping sucking, change in respiration rate. Note: Caregivers may be in denial about their child's hearing impairment.		
<b>9 MONTHS</b> If the answer is "No" to the language and hearing questions, examine both ears with an otoscope. If wax, foreign bodies or pus are not present, refer for a diagnostic hearing test. If pus, wax or foreign bodies are present this may be the cause of the hearing loss. Treat the cause or refer to Medical Officer and repeat otoscopy in 2 weeks. After 2 weeks, if the answer is still "No" or repeating the question, refer for a diagnostic hearing test and/or developmental assessment as appropriate.		
<b>18 MONTHS</b> If the answer is "No" to the language and hearing questions, examine both ears with an otoscope. If wax, foreign bodies or pus are not present, refer for a diagnostic hearing test, or if the child turns to sound but cannot point to feet/nose and say words, refer for developmental assessment, as this may indicate mental handicap. If pus, wax or foreign bodies are present this may be the cause of the hearing loss. Treat the cause or refer to Medical Officer and repeat otoscopy in 2 weeks. After 2 weeks, if the answer is still "No" or repeating the question, refer for a diagnostic hearing test and/or developmental assessment as appropriate.		

## **Appendix Two**

### **Research Participation Form**

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#### **PARTICIPATION IN RESEARCH PROJECT.**

Deaf Child Clinic - RXH Developmental Clinic

Sharon Kleintjes, a Clinical Psychologist working in the Department of Health, will be conducting research with parents of deaf children who attend the Deaf Child Clinic at the Developmental Clinic, Red Cross Hospital. The research is aimed at asking parents about:

- their **views** about being deaf and having a child who is deaf,
- whether there are issues which they as **parents** have had to consider when they have a child who is deaf,
- whether they have experienced the same or extra **child-rearing issues** when a child is deaf, and
- **services and organisations** they have found which support parents who have a deaf child.

This information will be used to make suggestions about support and services needed by parents who have a deaf child.

Parents are asked to volunteer up to 2 hours of their time to complete an interview about these issues. There is no obligation to take part, and children will continue to receive assistance at the Deaf Child clinic whether parents volunteer or not.

Information is confidential. Parents will be asked whether they would like parts of information they give to be fed back to the Team working with their child at the Deaf Child Clinic. No information will be shared without parent's permission.

The above information has been read by me and explained and I agree to take part in the research project.

NAME OF CHILD : \_\_\_\_\_ Date: \_\_\_\_\_

PARENT NAME (Mother) : \_\_\_\_\_ Signature: \_\_\_\_\_

PARENT NAME (Father) : \_\_\_\_\_ Signature \_\_\_\_\_

## Appendix Three

### Interview Guide

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INFORMANTS AT INTERVIEW

DATE OF INTERVIEW

HOME LANGUAGE

ADDRESS

TELEPHONE NO.

---

#### BACKGROUND INFORMATION

Child's name

Day care/Preschool

Date of Birth

Developmental Assessments

FAMILY GENOGRAM:

Sex of child

Miscarriages/Stillbirths?

Other deaf/disabled children/family members?

**Mother:** Age:                      Education:  
When/why stopped working?

Occupation now:                      before child  
Who cares for child while working?

**Father:** Age:                      Education:  
Any time away from home?

Occupation :                      Relationship status?  
Helps with child?

Others involved in childcare?

#### EARLY DEVELOPMENT OF CHILD

Pregnancy:    Planned?            Wanted?  
Accidents/illnesses/stress during pregnancy?

Mat. mental state?

Mat physical health?

Birth (NVD/C-section/Complications

Reaction to birth/maternal mental state

Early routine: mother-child relationship

Father's role

Response to baby's temperament

Babbling

First words

Sentences

Health/other disabilities

Influence of deafness?

Separations: daycare/school/hospitalisations

Influence of deafness?

Childcare: can N be left with someone?

Who?

Influence of deafness?

How do you feel about leaving N with someone?

## DEAFNESS/DIAGNOSIS

How did you come to realise N is deaf? (N's Age?)

What did you do?

Process to diagnosis?

When were you actually told N is deaf?

Who told you?

What did they say to you?

Did you take it in then?

How did you feel then?

How did you feel about how you were told?

Your partner?

How do you feel now?

What was helpful?

What was difficult?

What have you been told since?/Was it enough/What else should be told?

Do you know the cause of deafness?

When do you think it is best to be told?

What would you have changed?

Did you suspect before then? (What?)

How long has it been since the diagnosis?

Degree of acceptance of diagnosis?

What changes has the diagnosis brought (between partners/within family)?

## LANGUAGE AND COMMUNICATION

Have you been told how deaf N is?

Know the results of the last hearing test?

Is N fitted with a hearing aid?

How do you feel about N wearing the h/aid?

What ways sign/fingerspelling/gestures/lipreading/speech/a combination) do you use to communicate with N? other family members

Can N hear if you talk nearby?

Shout?

Without h/aid?

With h/aid?

Can N talk?

Be understood?

How does N tell you/explain things?

Can you understand? What's easiest?

Hardest?

Ho do you tell N/explain things?

How much/what does he understand?

Can N understand other people?

How does N and siblings communicate?

Does anyone tend to interpret for N?

What communication system has been suggested to you?

How has this worked?

What do you feel is the best language choice for N?

Any difficulty deciding on a choice?

Any difficulty actualising the choice?

Feelings about Sign Language?

Communication frustrations?

How do you cope with this?

Communication concerns?

## PRESENT DEVELOPMENT OF THE CHILD

**Self-help skills:**

Can N undress?

Dress?

Toilet care?

Bedwetting?

Washing self?

Grooming?

Tidy after self?

Helps with tasks?

Should N be doing more?

Difficulty teaching any of above?

Related to deafness?

**Mealtimes:**

Good or finicky eater?

Satisfied with table habits?

Does N make a lot of noise when (s)he eats?

What do you do?

Affected by Deafness?

**Bedtime:**

Any difficulty setting sleep routine?

Set bedtime?

Trouble getting N to sleep?

How do you cope with this?

N sleep alone or with someone? In your bed?

How does N let you know (s)he needs something?

What happens with night wakes?

Bedtime affected by Deafness?

**Play:** Can N play alone?

With other children?

Understood by other children?

How does N manage quarrels?

Any worries about N's play habits?

Any dangers?

Behaviour management and Discipline: How do you/your partner get on with N?

What do you enjoy

doing with N? What gets on your nerves about N?

Does N obey easily?

What happens if N does not obey?

Any tantrums? What do you do?

How do you discipline N?

How do you teach N not to be destructive in the house?

To stay away from dangers (hot stoves, plug points)?

Running in the road?



Can you get N's attention without going up to him/her? What's been the hardest to each N?  
Do you and your partner disagree on anything about raising N? How do you manage this?  
Do you/your partner treat N differently from other children? How? Why?  
Does your partner give enough support in raising N? Do you spoil/overprotect N?

### **PARENTS VIEW OF THEIR CHILD**

What do you like most about N? What do you think needs to change about N?  
What concerns you most about N? Is N functioning at full potential? If not, what's needed?

### **RELATIONSHIP ISSUES**

**With other people** re N's deafness: Difficulties/prejudice/How do you cope/feel?  
**Within the family**, are there any specific difficulties for N? How do you cope?  
Has N's deafness changed **your life** in any way?  
How do **your other children** relate to N?  
Has N influenced your decisions about **having more children**? How? Why?  
People say a deaf child can bring a couple closer or strain **the marriage**. Your experience?  
Has N's deafness affected your **view of yourself as a parent**? In which way?  
Has N's deafness brought any additional **financial** burden?

### **FUTURE**

Do you have any particular worries about N's future?  
What do you hope for N's future? What problems do you foresee?

### **GUIDANCE**

Do you have/need any help with N because (s)he is deaf? Who? What?  
Do you understand enough about N's deafness or need further explanations? About What?  
Do you know any deaf other people/families? Has this helped? How?  
What professional help have you had? Has this helped? Have there been any problems?  
Do you have contact with deaf organisations? Has this helped? Problems?  
Does N attend (pre)school? Happy/problems/consultation needed? If not, what do you plan ?  
  
Any suggestions you feel might be helpful to other parents of deaf children?

## Appendix Four

### (a) Interview Coding Sheet

	Theme	Theme code
1	Detection of deafness/Finding out	Detection
2	Impact of news	Impact
3	Help-seeking	Help
4	Child's development and Progress	Progress
5	Other 1: Other disabilities	Add Disability
6	Language and communication skills	Comm
7	Self Help Skills	Selfhelp
8	Social Skills	Social skills
9	Daily Routine of Child	Routine
10	Disciplining the child	Discipline
11	Relationship with Child	Relchild
12	Relationship with Partner	Relpartner
13	Relationship with Family	Relfam
14	Relationship with Neighbours	Relneigh
15	Relationship with Professionals	Relatprof
16	Parental stress	Stress
17	Emotional impact	Emotionimpact
18	Economic impact	Econimpact
19	Social Impact	Socimpact
20	Knowledge about resources	Resources
21	Support received	Supportrec
22	Support needed	Supportneed
23	Future concerns	Concerns
24	Other 2: Maternal mental health	Maternal MH
25	Other 3: Language Choices	Langchoices
26	Other 4: Educational Choices	Educatchoices

Extract from  
Interview with Mother and Father, Child GNS

Question  
You said that he was in a ... since he was two. When did you sense that there might be something wrong? detect

Answer  
At ten months, the clinic system picked it up.

Question  
That he had a hearing problem?

Answer  
Yes.  
Father - her father picked it up before them.

Question  
What did your father noticed?

Answer  
He would just always say to us, you know there is something wrong with this child. Now my husband is someone who can very pre-occupied with himself and he can go off for hours on his own and he can be quite happy with it. I would just think, oh genetic so just leave N to be. And also I think where minds get absorbed in a real defect, like ... had. Then you can't somehow believe that your other child is somehow going to be fine. It just cannot happen to two children. You know just don't believe it. I think it to a large extent, I think it was in terms of my personality and nature and type of work that I did. You always look at where the problem areas are so, I mean I never noticed it. If I think about it now there must have been a couple of signs but you just convinced yourself, it's not there. My dad was very honest with me, one day we sat in the room and he said to me, don't care what you think "die kind is doof". And I said to him don't say that and he took two glass plates and he banged it and said nobody is that pre-occupied that they can ignore if I break these glass plates.

Question  
Was it very difficult for you to ...?

Answer  
I tell you I always maintain that I found that far more dramatic and it was very difficult because I always calmed myself into believing that this could only happen to our child.

Question  
It still quite difficult?

Answer

Picked up at 10 mths (clinic)

Picked up family before 10 mths

Add Disab. Detection Awareness?

Additional child with disability  
Acceptance of diagnosis  
difficult, delayed picking up -> 2nd child with disability

Sharon on Parent

It is still difficult. I think I deep down inside, you become so involved in your children's problems, that you actually down allow yourself to become angry, you don't allow yourself to cry, you don't allow yourself to get too involved about the situation, about the sacrifices that you have to make for your children. So you keep on telling yourself you know that you are suppose to be responsible for your children and which you are suppose to be but you just neglected yourself.

Question  
And it doesn't change the fact that it is always hard.

Answer (daughter)  
Yes. Especially now when it's ... ops is almost finish but now we sort of realize that N is a lifelong thing.

Question to father  
What has your feelings been around this?

Answer - father  
I was very upset, very distress. Basically because it's not going to go away. It is something that we already have to think about now, what does the future hold for him and how can one actually somehow emotionally, physically and every possible way support him for a future where he will not sort of really, where he can almost make a positive thing out of a handicapped....

Sharon - he can reach full potential.....

Father - yes. So that is a very big concern the way the world is going. Where should one... what should actually work towards.

Sharon - I understand what you are saying.

Father - because it's something that has to start now. Academics, doing things with his hands, business or something. Well this is my ... for a child with a handicap like that. He should start something now so that it can grow and somehow be his future.

Question  
Is that your view? (to Mother)

Answer  
You know I don't even want to think about it.

Question  
You haven't thought about it, you are just dealing with it at this time?

Impact of News

Stress

Impact

Stress Emot Impact

Future Concerns

Future Concerns

Emotional Impact Stress

Dealing with nature on a moment to moment basis is a way to cope with things feel overwhelming

Answer

Yes. I'm clearly not ready to have a

(Avoidance as a means of coping?)

Question

So at ten months your dad and the sister picked it up and your dad was talking about it, did the sister say she thought he might have a hearing problem?

Answer

We really didn't ... by the time the sister did the last test with the rattle and then I knew so I thought now I'm going to take him for tests. He was tested by ... van Zyl at the Tygerberg Hospital and initially when they made, what do you call that one where they make you to sleep and do the test. They did something to him that made him to sleep. When they did that on him somehow they came to a conclusion that the hearing in the right ear was very, the loss of the ear was very bad but the left ear, he could almost hear about 80 - 85%. And then they felt that any child who has at least almost perfect hearing why should they be able to the ... language and that they probably need not to mention. But fortunately for us three months later, they re-tested him just as a routine check up and they realized that the hearing in the other ear was also just as bad as the other one. Then he was fitted with first one hearing aid because they thought maybe just the one ear needs to be picked up. It took ... he was almost three when he had his second hearing aid. But by time that he was already in their class.

Deafness  
Profound

Deaf

Family results  
deaf

Question

And when you feeling constraint by the person that....?

Answer - father

The Methodist - they gave us tremendous support.

Question

Between ten months and....?

Answer

Well looked he had his tests, he tests was taking place and looked he went to the class to, but we attended the parent guidance class. It's about a year and half that we started.

Father - I'll say it's only very recently that we realized how profoundly deaf he was.

Question to father  
How did you...?

Answer - father

I knew there was a problem but I never actually realized that it was profound.

Prof Relat

(Comm with Parents?)

Difficulties for Parents



Communication to parents  
Acceptance of Deafness

Question to father

Mr. St... what happened that realized...?

Answer - mother

Well all of the hearing assessments that they've done.

Father - actually just a little while ago I did a test here at Groote Schuur and then I overheard some of the therapists talking to one another and then I heard that his hearing was quite profound.

Question

Did you...?

Answer - mother

We've been told that his got a severe hearing multi frequency and quite frankly it doesn't really say anything. High frequencies, this sound, that sound, you won't be able to hear and then we ... audio-grams and I suppose to a very large... you can feel as they have to protect people and so they try and use as much jargon to sort of colour their thing in almost beautiful. So that you know there is a lost and you know your child needs their help and he suffers the impact and you don't fully realize just what it is. I mean now recent with my mom every now and then she would say he is speaking so well why must he go to a special school. Why can't he go to a normal school, must the child now wear these hearing aids for the rest of his life. So the other day I sat her down and I told her, you know mom you got a deaf grandchild and she said but you said that he's hearing impair. So I said yes, I'll explain the words like everybody else does. I said N... is deaf and I mean she was shocked. And this morning she said to me I think I must give you money for an extra ... so that N... can get out. They are only realizing now. I suppose it's much easier telling people that your child is hearing impair.

(Counselling of parents need to be direct, progressive regular updates?)

Refam Impact

Question

I wanted to check at the beginning with you what kind of terminology you using because it's kind of important to have the terminology sorted out because that might actually...?

Answer

The health concepts yes of not labeling. It often gives people a measure of comfort but at the same time you haven't told the truth. And I think to a very large extent, one actually can obviously prepare yourself for what lies ahead in the ... what it's all about.

Question

So you were both saying that he was hearing impaired

Answer

What's told to parent, language used can confuse, diffuse the information

## Appendix Five

### Questionnaire

In: Moores, D.F., & Meadows-Orlans, K.P. (eds.). (1990). Educational and Developmental Aspects of Deafness. Gallaudet University Press, Washington D.C., pp 335-336.

#### Impact of Childhood Hearing Loss on the Family: A Questionnaire for Parents

Please answer ALL questions as honestly as you can. Circle SA if you STRONGLY AGREE. Circle "a" if you "agree". Circle "d" if you "disagree". Circle SD if you STRONGLY DISAGREE.

1	I often regret the extra time our family must devote to the problems of hearing impairment.	SA	a	d	SD
2	I can feel proud of the way I have responded to the special needs of my hearing impaired child	SA	a	d	SD
3	Differing opinions from professionals have made it hard for me to make decisions about schooling for my hearing impaired child.	SA	a	d	SD
4	We have more family arguments about our hearing impaired child than we have about other things.	SA	a	d	SD
5	My communication skills are quite adequate for my child's needs.	SA	a	d	SD
6	I feel satisfied with the educational progress of my hearing impaired child.	SA	a	d	SD
7	Much of the stress in my family is (was) related to deafness.	SA	a	d	SD
8	I wish I could communicate as well with my hearing impaired child as I do with (my) hearing child(ren).	SA	a	d	SD
9	I've had a lot of good professional advice about education for my hearing impaired child.	SA	a	d	SD
10	My hearing impaired child's behaviour has often been a source of worry to me.	SA	a	d	SD
11	I wish some of the other members of my family could communicate more easily with my hearing impaired child.	SA	a	d	SD
12	Sometimes my friends/neighbours have been thoughtless or cruel about my child's hearing loss.	SA	a	d	SD
13	Family and friends usually treat my hearing impaired child the same as they would treat a hearing child of the same age.	SA	a	d	SD
14	I tend to treat my hearing impaired child like a child who is a good deal younger.	SA	a	d	SD
15	Many times I have been angry because of the way professionals treated me as the parent of a hearing impaired child.	SA	a	d	SD
16	Because of hearing loss, it was (is) necessary for me to forget many hopes and dreams that I had for my child.	SA	a	d	SD

**Impact of Childhood Hearing Loss on the Family: A Questionnaire for Parents (continued)**

17	My hearing impaired child is often left out of family conversations because of communication problems.	SA	a	d	SD
18	I have no regrets about the educational opportunities that have been available to my hearing impaired child.	SA	a	d	SD
19	In the preschool years, my child's hearing loss created so many demands that I never have time for myself.	SA	a	d	SD
20	I feel confident that my hearing impaired child can handle most situations as well as a hearing child.	SA	a	d	SD
21	It was really hard to find a doctor who could tell us that our child has a hearing loss.	SA	a	d	SD
22	Parents of hearing impaired children are expected to do too many things for them. This has been a burden for me.	SA	a	d	SD
23	There are many things I can't seem to communicate to my hearing impaired child.	SA	a	d	SD
24	It is frustrating for me as a parent to have so many different opinions among professionals who work with hearing impaired children.	SA	a	d	SD

## Appendix Six (a)

### Questionnaire Results: Raw Data: Scale One: Stress Factors

#### KEY

SD = strongly disagree  
D = disagree  
A = agree  
SA = strongly agree

Score 1 = strongly positive attitude (low stress)  
Score 2 = positive attitude  
Score 3 = negative attitude  
Score 4 = strongly negative attitude (high stress)

		PARTICIPANTS 1-10									
QN NO	QUESTION	1PMP	2APM	3AW	4YG	5YH	6NS	7SM	8DR	9RR	10ZK
1	Regret time have to invest in deafness	SD 1	SD 1	SD 1	D 2	SD 1	D2	SD 1	SD1	D2	A3
4	More arguments re deafness	SD 1	SD 1	SD 1	SD 1	D 2	D2	SD 1	SD1	D2	A3
7	Family stress due to Deafness	D 2	SD 1	SD 1	D2	SD 1	D2	SD 1	D2	D2	?D2
10	Child's behaviour is a worry	A 3	D 2	D 2	SA 4	SD 1	A3	SD 1	D2	A3	D2
13	Fam /friends treat child same as same age hearing child	SA 1	D 3	D 3	D 3	A 2	A2	D 3	D3	A2	A2
16	Have to forget Hopes/dreams	SD 1	D2	SD 1	A 3	SD 1	A3	D2	A3	D2	A3
19	Demands of deafness = no time for self	SA 4	A 3	SD 1	SD 1	A 3	A3	A3	D2	SA3	D2
22	Expectations of me a burden	D 2	D 2	SD 1	SD 1	D 2	D2	D2	D2	D2	D2
	<b>STRESS RATING</b>	<b>15</b>	<b>15</b>	<b>11</b>	<b>17</b>	<b>13</b>	<b>19</b>	<b>14</b>	<b>16</b>	<b>18</b>	<b>19</b>

PARTICIPANTS 11-20											
QN NO	QUESTION	11TK	12JM	13AB	14TR	15MM	16NW	17LP	18MA	19KA	20AW
1	Regret time have to invest in deafness	D2	SD1	SD1	SD1	D2	SD1	D2	D2	SD1	D2
4	More arguments re deafness	D2	SD1	SD1	SD1	D2	D2	D2	D2	D2	D2
7	Family stress due to Deafness	D2	SD1	D2	D2	D2	D2	D2	D2	SD1	D2
10	Child's behaviour is a worry	A3	SD1	A3	D2	A3	D2	A3	D2	D2	D2
13	Fam /friends treat child same as same age hearing child	A2	SA1	SA1	A2	A2	A2	D3	D3	D3	A2
16	Have to forget Hopes/dreams	D2	SD1	D2	D2	D2	D2	D2	D2	D2	D2
19	Demands of deafness = no time for self	D2	D2	SD1	D2	D2	D2	D2	D2	SD1	D2
22	Expectations of me a burden	D2	Sd 1	D2	D2	D2	D2	D2	D2	D2	D2
	<b>STRESS RATING</b>	<b>17</b>	<b>9</b>	<b>13</b>	<b>14</b>	<b>17</b>	<b>15</b>	<b>18</b>	<b>17</b>	<b>14</b>	<b>16</b>



## Appendix Six (b)

### Questionnaire Results: Raw Data: Scale Two: Communication Factors

#### KEY

SD = strongly disagree

A = agree

D = disagree

SA = strongly agree

Score 1 = strongly positive attitude (low communication difficulties)

Score 2 = positive attitude

Score 3 = negative attitude

Score 4 = strongly negative attitude (high communication difficulties)

		PARTICIPANTS 1-10									
QN NO	QUESTION	1PM P	2APM	3AW	4YG	5YH	6 NS	7SM	8DR	9RR	10ZK
2	Proud of response to deafness	SA 1	SA 1	SA 1	A 2	A 2	A2	SA 1	SA1	SA1	A2
5	Communication skills adequate	SA 1	SA 1	D 3	A 2	A 2	D3	A2	D3	SA1	D3
8	Wish to communicate with deaf child as well as with hearing	A 3	D 2	D 2	SA 4	SD 1	SA4	A 3	SA4	A3	?D2
11	Wish family can communicate more easily with child	A 3	A 3	A 3	SA 4	SD 1	SA4	D 2	A3	SA4	SA4
14	I treat child younger	SA 4	SD 1	D2	SD 1	SD 1	D2	SA 4	A3	D2	D2
17	Child left out of conversations	A 3	D 2	SD 1	SD 1	SD 1	A3	A3	A3	D2	?SD1
20	Child handles most situations on par with hearing child	SA 1	A 2	D 3	SA 1	A 2	A2	D3	D3	A2	D3
23	Many things I cant communicate to child	A 3	D 2	A 3	D 2	D 2	A3	A3	A3	D2	A3
	<b>Communication RATING</b>	19	14	18	17	12	23	21	23	17	20

		PARTICIPANTS 11-20									
QN NO	QUESTION	11TK	12JM	13AB	14TR	15MM	16NW	17LP	18MA	19KA	20AW
2	Proud of response to deafness	A2	SA1	SA1	A2	A2	SA1	A2	A2	SA1	A2
5	Communication skills adequate	D3	SA1	SA1	A2	D3	A2	A2	D3	D3	A2
8	Wish to communicate with deaf child as well as with hearing	A3	SD1	SD1	D2	A3	A3	A3	A3	A3	A3
11	Wish family can communicate more easily with child	A3	D2	SD1	D2	A3	SA4	SA4	A3	A3	A3
14	I treat child younger	A3	SD1	A3	A3	A3	D2	D2	A3	A3	A3
17	Child left out of conversations	D2	D2	D2	D2	D2	D2	A3	A3	A3	D2
20	Child handles most situations on par with hearing child	D3	SA1	SA1	A2	D3	A2	A2	D3	D3	A2
23	Many things I cant communicate to child	A3	D2	D2	D2	A3	A3	A3	A3	A3	D2
	<b>Communication RATING</b>	<b>22</b>	<b>11</b>	<b>12</b>	<b>17</b>	<b>22</b>	<b>19</b>	<b>21</b>	<b>23</b>	<b>22</b>	<b>19</b>

## Appendix Six (c)

### Questionnaire Results: Raw Data: Scale One: Relationship Factors

#### KEY

SD = strongly disagree

A = agree

D = disagree

SA = strongly agree

Score 1 = strongly positive attitude (low relationship difficulties)

Score 2 = positive attitude

Score 3 = negative attitude

Score 4 = strongly negative attitude (high relationship difficulties)

		PARTICIPANTS 1-10									
QN NO	QUESTION	1PM P	2APM	3AW	4YG	5YH	6 NS	7SM	8DR	9RR	10ZK
3	Differing opinions on school	SD 1	D 2	D 2	D 2	NA1	SA1	SD 1	NA1	SA4	D2
6	Satisfied with educational progress of child	SA 1	SA 1	A 1	SD 4	SA 1	D3	SD 4	NA1	A2	?D3
9	Good Prof advise re education	A 2	SA 1	SD 4	D 3	NA1	D3	D 3	SD4	D3	?D3
18	No regrets re educational opportunities	A 2	NA1	NA1	NA1	SA 1	SD4	D3	NA1	D3	?D3
12	Friend/neighbour can be cruel	SD 1	SA 4	D 2	SD 1	SD 1	D2	SD 1	SD1	D2	D2
15	Feel anger at professional treatment	SD 1	A 3	SD 1	SD 1	D 2	D2	D 2	A3	SA4	D2
21	As hard to find doctor to diagnose hearing loss	SA 4	D 2	SD 1	SD 1	SA 4	D2	D2	SA4	SA4	D2
24	Different professional opinions on deafness frustrating for me	SD 1	D 2	D2	SD 1	A 3	SA4	D2	SA4	SA4	D2
	<b>Relationship RATING</b>	<b>13</b>	<b>16</b>	<b>14</b>	<b>14</b>	<b>14</b>	<b>21</b>	<b>18</b>	<b>19</b>	<b>26</b>	<b>19</b>

PARTICIPANTS 11 - 20											
QN NO	QUESTION	11TK	12JM	13AB	14TR	15MM	16NW	17LP	18MA	19KA	20AW
3	Differing opinions on school	A3	SD1	NA1	D2	D2	D2	A3	A3	D2	D2
6	Satisfied with educational progress of child	D3	SA1	NA1	A2	D3	A2	D3	D3	A2	A2
9	Good Prof advise re education	D3	SA1	SA1	A2	D3	D3	D3	SD4	A2	A2
12	No regrets re educational opportunities	D2	SD1	SD1	D2	D2	D2	SA4	D2	SD1	D2
15	Friend/neighbour can be cruel	D2	D2	A3	D2	D2	D2	A3	D2	SD1	D2
18	Feel anger at professional treatment	D3	D3	NA1	A2	NA1	NA1	D3	D3	A2	A2
21	As hard to find doctor to diagnose hearing loss	A3	SA4	D2	A3	D2	D2	A3	D2	D2	D2
24	Different professional opinions on deafness frustrating for me	D2	SA4	D2	D2	D2	D2	A3	D2	D2	D2
	<b>Relationship RATING</b>	21	17	12	17	17	16	25	21	14	16

## Appendix Seven

### Questionnaire Results: Summary Data

Scoring Key for summarised data:

Score range	Stress/Difficulty Rating
8 - 15	Low Stress/Difficulty (L)
16 - 23	Medium Stress/Difficulty (M)
24 - 32	High Stress/Difficulty (H)

Table 7(a): Summary scores for individual respondents per scale\*

PARTICIPANTS 1 - 10										
SCALE	1PM P	2APM	3AW	4YG	5YH	6 NS	7SM	8DR	9RR	10ZK
STRESS RATING	15L	15L	11L	17M	13L	19M	14L	16ML	18M	19M
COMMUNICATION	19M	14L	18M	17M	12L	23M	21M	23MH	17M	20M
RELATIONSHIP	13L	16ML	14L	14L	14L	21M	18M	19M	26H	19M
OVERALL RATING	L	L	L	M	L	M	M	M	M	M

PARTICIPANTS 11 - 20										
SCALE	11TK	12JM	13AB	14TR	15MM	16NW	17LP	18MA	19KA	20AW
STRESS RATING	17M	9L	13L	14L	17M	15L	18M	17M	14L	16ML
COMMUNICATION	22M	11L	12L	17M	22M	19M	21M	23MH	22M	19M
RELATIONSHIP	21M	17M	12L	17M	17M	16ML	25H	21M	14L	16ML
OVERALL RATING	M	L	L	M	M	M	M	M	L	M

\* 6 children with a confirmed additional disability (column shaded) and 2 children with suspected additional disability (number shaded)

Table 7(b): Summary scores per scale

SCALE	HIGH (H)	MEDIUM (M)	LOW (L)
STRESS	0	10	10
COMMUNICATION	0	16	4
RELATIONSHIP	2	12	6

**Table 7(c): Summary scores per scale as a proportion of the deaf (14) and additionally disabled (6) children.**

SCALE	GROUP	TOTAL	HIGH (H)		MEDIUM (M)		LOW (L)	
			No.	%	No.	%	No.	%
STRESS	All	20	0	0	10	50	10	50
	Deaf	14	0	0	7	50	7	50
	Additional Disability	6	0	0	3	50	3	50
COMM.	All	20	0	0	16	80	4	20
	Deaf	14	0	0	11	78.57	3	21.43
	Additional Disability	6	0	0	5	83.33	1	16.67
RELAT.	All	20	2	10	12	60	6	30
	Deaf	14	1	7.14	9	64.29	4	28.57
	Additional Disability	6	1	16.67	3	50	2	33.33
OVER.	All	20	0	0	13	65	7	35
	Deaf	14	0	0	10	71.43	4	28.57
	Additional Disability	6	0	0	3	50	3	50